

**A Pilot Study Investigating the Effectiveness of a Mindfulness Based  
Stress Reduction (MBSR) Course Designed Specifically for Parents of  
Children with Chronic Illnesses**

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## **Declaration**

I, Corrie Darbyshire, declare that this thesis was written by me and that I conducted the work detailed herein. This work has not been submitted for, or accepted in, any previous degree.

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## **Abstract**

**Objectives:** To evaluate the effectiveness of a six-week Mindfulness Based Stress Reduction (MBSR) course, specially designed for parents of chronically ill children. The course aimed to increase mindfulness and enhance psychological well-being in participants. It also aimed to reduce perceived difficulties associated with parenting and improve perceptions of child well-being.

**Design:** A within subjects repeated measures design was used.

**Method:** Nine participants were recruited to take part in an MBSR course that included components of MBCT and ACT. Participants attended six weekly group meetings and carried-out daily home-based mindfulness practice. Measures were administered pre-treatment, post-treatment and three-months follow up.

**Results:** Immediately post-treatment, participants were significantly more mindful and reported significantly lower levels of anxiety, depression and parenting distress, than at baseline. These gains were maintained at three months follow-up. No significant differences were observed in participants' perceptions of their child's well-being across the time points.

**Conclusion:** A brief MBSR course has the potential to enhance the well-being of distressed parents who have chronically ill children. These findings support the conduct of a randomised control trial.



## **Chapter 1: Introduction**

### **1.1 The Rise in Incidence of Chronic Childhood Illness**

Advances in medicine and modern technology have increased the survival rates of children with chronic illness, including illnesses that were previously considered to be fatal. For example, the proportion of children in the United Kingdom (UK) who were alive five years after the diagnosis of cancer has dramatically increased from 12 percent, between 1962 and 1971, to 50 percent, between 1975 and 1979, to 76 percent, between 1995 and 1999, and to over 80 percent at present (Campbell *et al.*, 2004; Cancer Research UK, 2005; Moller *et al.*, 2001). The median survival rate for cystic fibrosis has also increased from less than one year of age in 1940 to approximately 16 years in 1970 and 33 years in 2000 (Orenstein *et al.*, 2002). The mortality rate for asthma (per 100 000 children aged 1-16 years) has also declined from 49.9 in 1968 to 16.3 in 2000 (Panickar *et al.*, 2005). The implications of such improvements are that more children are now living with chronic illnesses.

The Scottish Health Survey states that approximately 19 percent of boys and 11 percent of girls aged between birth and 15 years suffer from at least one long-standing illness (Bromley *et al.*, 2003). A childhood chronic illness is typically defined as a health condition that is long-lasting (e.g., 3 months or longer) that also involves one or more of the following: dependency on medical technology, medication, special diet, more medical care than is expected for the child's age or special ongoing treatments, as well as a potential limitation of age-appropriate functions or disfigurement (Medicine Net, 2003; Jackson & Vessey, 2000). Examples of chronic illnesses that affect children, other than those already mentioned, include diabetes, seizure disorders, congenital heart disease, juvenile rheumatoid arthritis, sickle cell disease, neuromuscular disease, dermatological conditions and chronic haematological disorders.

## **1.2 The Experience of Chronic Illness from the Perspective of the Ill Child**

In addition to the typical developmental challenges faced by children while growing up, children with chronic illnesses are often faced with a number of additional illness-related demands. These might include school absences, days of reduced activity, and the management of pain, diet and treatment. All of these factors have the potential to cause frustration, if perceived by the child to be interfering with their desired goals (Immelt, 2006). The visibility of the child's condition may also trigger self-consciousness and negative feelings about physical appearance (Immelt, 2006), whereas for other children having to comply with a life-altering treatment regime may instil in them a sense of being different. In addition to this, in comparison to healthy youngsters, children who have chronic illnesses might be more dependent on their parents and for longer periods of time, due to parents' role in the management and supervision of their treatment regime. This might impact on the child's ability to develop independence and their self-identity to the same degree as their peers, potentially leading to low self-esteem.

Children might also suffer from a range of condition-specific difficulties. For example, children with cystic fibrosis, a condition in which the lungs and digestive system, including the pancreas, become clogged with sticky mucus, have difficulty breathing and digesting food. The latter means that children with this condition are often slight, with short stature, and can experience delayed puberty, which can result in them being subject to teasing and bullying by their peers (Bluebond-Langner *et al.*, 2001; Hardin *et al.*, 2005). The treatment regimes for children with this condition are often extensive and can result in strong feelings of resentment, frustration, stress and low mood in the affected child (Bernard & Cohen, 2003). For example, extensive physiotherapy exercises are often required to clear the airways of mucus, which can take up to 45 minutes three times per day. Children with this condition are also required to pay particular attention to ensuring that they eat a high calorific diet, which can mean that meal times become a burden rather than a pleasurable experience.

Children with chronic renal disease, a serious illness that causes severe and irreversible reduction in kidney function, can also experience profound, disease-specific, implications for their lives. For example, these children often experience various challenges (especially as the disease progresses), such as maintaining a restricted dietary and fluid regime, chronic dependence on medical equipment, very obvious physical changes associated with transplantation, and the knowledge that they will live their whole lives with the recurrent cycle of dialysis and transplantation (Goldstein *et al.*, 2007). This also means that the affected child will experience, sometimes prolonged periods, in which they are seriously unwell and in which the quality of their life is extremely poor and then, following transplantation, being required to adjust to the fact that they are no longer chronically sick and in many cases can lead a normal life (Soliday *et al.*, 2000). Despite this, even after transplantation, regular hospital visits are often necessary and there is often concern and uncertainty about the future (Goldstein *et al.*, 2007). Understandably, for children (and their families), this can seem like an ‘emotional rollercoaster’ and children with such conditions often experience high levels of anxiety, as well as issues around body image (Henning *et al.*, 1988). Research has also demonstrated that children with chronic renal disease can experience associated cognitive impairments, including problems with memory and concentration, which can affect educational attainment, leading to low self-esteem (Goldstein *et al.*, 2007; Slickers *et al.*, 2007).

### **1.3 The Experience of Chronic Illness from the Parents’ Perspective**

Chronic illness in childhood is not only experienced as challenging for the child, but for the whole family (Hodgkinson & Lester, 2002). Indeed, research indicates that family functioning is often affected by the tasks of adapting to life with a chronically ill child (Pursell, 1994) and parents may struggle to balance the demands of keeping their child healthy (i.e., complying with treatment regimes), helping them to progress through age-appropriate developmental stages and ensuring that they are happy and able to participate in life as fully as possible.

### **1.3.1 *Demands of Parenting***

Parenting in itself is not an easy task. There are a wide range of parenting behaviours that are important in order to enhance a child's emotional, social, cognitive, behavioural and physical development and well-being (see Amato & Fowler, 2002 for review). Some of these include, remaining vigilant in order to keep your child safe from harm, recognising and addressing their emotional needs, displaying warmth and approval, providing clear, firm and respectful directions, encouraging and rewarding positive behaviours, setting limits for undesirable behaviours and following through with non-coercive discipline strategies. Parents are also required to manage interpersonal conflict and to regulate their own affect, in order to respond to their child's behaviours in appropriate and consistent ways (Amato & Fowler, 2002; Forgatch & DeGarmo, 1999).

### **1.3.2 *Challenges Involved in Caring for a Chronically Ill Child***

As with other factors such as poverty and deprivation, unhealthy marital relationships and poor parental mental health, having a child with a chronic condition poses additional challenges to the parenting role (Dempsey, 2008; Royal College of Paediatrics and Child Health, 2002). For example, parents may become primary healthcare providers, taking on major responsibility in the day-to-day management of their child's illness (Bradford, 1997). This might include learning how to carry out the medical aspects of their child's care, ensuring that necessary lifestyle changes are adhered to, developing the knowledge and skills to accurately monitor their child's symptoms and making clinical decisions based on this information (Ray 2002). For example, a parent of a child with Type 1 diabetes may be required to: monitor blood glucose levels; give or supervise insulin injections (which may be required up to four times per day); plan meals and snacks; and supervise exercise levels to ensure high levels of exercise are not performed during times of insulin deficiency and to ensure additional carbohydrate is obtained if necessary (Daneman *et al.*, 1999). Parents are also required to be vigilant for signs of hypoglycaemia (low blood glucose levels) and hyperglycaemia (high blood glucose

levels), which can lead to coma and death if not treated appropriately (Daneman *et al.*, 1999).

As well as supervising the day-to-day treatment requirements, parents are also often required to attend a number of clinic appointments with their child. Multiple hospital visits or inpatient stays also means that the child may be absent from school more frequently, which may require parents to provide additional educational support within the home (Cuskelly *et al.*, 1998). When a child is chronically ill, parents are often required to stop working or to reduce their hours (Fewell, 1993; VandenHeuvel, 1997). However, research suggests that some parents of chronically ill children report benefits from being able to go to work, which may provide a break from the intensity of the caregiving situation (Major, 2003).

In addition to this, the literature states that parents of chronically ill children often experience greater relationship strain than parents of healthy children, including higher rates of marital conflict and less time spent with friends and the extended family (Ray, 2002). This might help to explain why parents of chronically ill children often report a strong sense of isolation (Silver *et al.*, 1999).

### **1.3.3 *Emotional Impact of Caring for a Chronically Ill Child***

Many chronic illnesses in young children are also unstable, in that they are characterised by fluctuations in symptom severity and changes in the course of the illness. This means that parents may be presented with multiple stressful events on a regular basis (Krulik *et al.*, 1999). Having a child with a chronic illness can challenge a parent's belief that they have a responsibility to protect their child, to prevent harm and to ease their pain, resulting in high levels of distress (Zelikovsky *et al.*, 2007).

Bonner *et al.* (2005) highlighted specific difficulties often experienced by parents of chronically ill children, including illness related uncertainty and chronic sorrow. Illness



related uncertainty was defined as 'both acute and ongoing or pervasive fear of possible illness consequences' (Bonner *et al.*, 2005, p.311). A recent review of the literature on uncertainty experienced by parents of children with chronic illnesses also highlighted a relationship between uncertainty and psychological distress, including anxiety, depression and feelings of helplessness (Stewart & Mishel, 2000). Chronic sorrow, experienced by a parent in relation to their child's illness, has been defined as long-lasting feelings of grief, sadness and disappointment, in response to repeated losses experienced over the course of their child's illness (Bonner *et al.*, 2005).

It has been well-documented that parents of children with chronic health problems report heightened levels of stress in comparison to parents of healthy children. This finding is consistent across various conditions, including cystic fibrosis (Hodgkinson & Lester, 2002), congenital heart disease (Goldberg *et al.*, 1991), diabetes (Streisand *et al.*, 2005), cancer (Libov *et al.*, 2002), asthma (Parker & Lipscombe, 1979), juvenile rheumatoid arthritis (Manuel, 2001), Duchenne muscular dystrophy (Holroyd & Guthrie, 1986) and feeding/ swallowing problems (Sullivan *et al.*, 2000). A study conducted by Krulik *et al.* (1999), also replicated these findings with mothers of chronically ill children from different cultural backgrounds. Although the majority of studies investigating stress associated with parenting a chronically ill child have involved mothers, Sloper (2000) conducted a study involving both mothers and fathers of children who were suffering from cancer. Results were consistent with the elevated levels of stress reported in previous studies, indicating that 51 percent of mothers and 40 percent of fathers reported high levels of stress at both 6 and 18 months following the diagnosis of their child's condition.

Research also suggests that high levels of parenting stress may put both mothers and fathers at an increased risk for further poor psychological adjustment, including the development of depressive and anxiety disorders (Cohen, 1999; Farley *et al.*, 2007; Thompson *et al.*, 1992; Zelikovsky *et al.*, 2007). Indeed, research suggests that parents of children with chronic medical conditions are more likely to experience mental health

problems, in comparison to parents of healthy children (Kazak *et al.*, 1988; Mastroyannopoulou *et al.*, 1997).

There appear to be a number of factors that mediate the relationship between parenting stress and further psychological problems in parents. For example, certain coping mechanisms used to manage stress have been proposed to play a role in the way that parents experience the events associated with their child's medical condition. Whereas certain coping styles (e.g. seeking social support, positive reappraisal) have been found to reduce the distress experienced by parents of chronically ill children (Meleski, 2002), other attempts to cope have been associated with heightened psychological distress in parents, across various childhood illness categories (Wallander *et al.*, 2003). For example, the use of cognitive avoidance (e.g. wishful thinking) was found to be associated with depression in parents of children with Turner syndrome (Faust *et al.*, 1995) and in mothers of children waiting to have a kidney transplant (Zelicovsky *et al.*, 2007). Rumination and worry, which are characterised by negative cyclic thinking about the past and the future, respectively, have also been frequently reported in studies involving parents of children with various chronic illnesses, including leukaemia, solid tumours, diabetes, epilepsy and children awaiting bone marrow transplantation (Goldbeck *et al.*, 2001; Kronenberger *et al.*, 1998). Although this may be an attempt for these parents to begin to make sense of their apparently unpredictable and uncertain situations, research suggests that these styles of thinking are associated with increased emotional distress in parents (Goldbeck *et al.*, 2001; Kronenberger *et al.*, 1998).

#### **1.4 Emotional and Behavioural Problems in Chronically Ill Children**

It is not only parents of chronically ill children that are at an increased risk of developing adjustment problems, but it is the child too. According to Cohen (1999), 'compared with healthy peers, children with ongoing health conditions are at a greater risk of mental health problems...emotional disorders, abnormal behavioural symptoms, and school-related adjustment problems' (p.149). In a meta-analytic review of 87 studies, Lavigne

and Faier-Routman (1992) found that children with chronic physical illnesses were at an increased risk of emotional problems (e.g. stress, anxiety & depression) and behavioural problems (e.g. inattention, deviance, impulsivity, aggression & peer relationship difficulties).

Furthermore, Glazebrook *et al.*, (2003) conducted a UK based study involving 307 children who were suffering from chronic illnesses and 10,438 healthy children and assessed them using the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997), for the presence of emotional and behavioural disturbance. Their results demonstrated that children with chronic illnesses were more than twice as likely to score within the abnormal range on the SDQ. However, the discrepancy between children with chronic illness and healthy controls appeared to be much more marked for emotional symptoms (24.1% & 10.7%, respectively) than for behavioural problems (20.9% & 15.1%, respectively).

## **1.5 Factors Contributing to Emotional and Behavioural Problems in the Child**

Various factors have been proposed to contribute to the higher incidence of emotional and behavioural problems found in children with chronic illnesses. These include receiving a diagnosis, the severity of the child's illness and the limitation of usual childhood activities (Bennett, 1994; Cadman *et al.*, 1987; Stein & Jessop, 1984). However, research in this area is equivocal and some studies have not found an association between these factors and poor child adjustment (Immelt, 2006).

### **1.5.1 Parental Psychological Well-Being**

Conversely, research conducted over the past 25 years has consistently identified family functioning as an important predictor of psychological wellbeing in children with chronic illnesses (Bonner *et al.*, 2005). For example, a study conducted by Rutter (1981) demonstrated that 20 to 25 percent of chronically ill children in poorly functioning families were classified as having a psychiatric disorder, whilst this was true for only



seven percent of chronically ill children in well functioning families. According to Schor (2003) 'families are the most central and enduring influence in children's lives. Parents are also central in pediatric care... the health and well-being of children are inextricably linked to their parents' physical, emotional and social health, social circumstances, and child-rearing practices' (p.1541). Given the relatively high levels of psychological distress among parents of chronically ill children, this might help to explain the higher incidence of emotional and, to a lesser degree, behavioural problems in children with chronic illnesses.

There is a large body of research indicating that poor psychological wellbeing in parents, including parenting stress, anxiety and depression, is associated with both short- and long-term reductions in the emotional, physical and social wellbeing of children (Beardslee *et al.*, 1998; Melamed & Ridley-Johnston, 1988; Rutter, 1966; Smith, 2004; Weissman *et al.*, 1997, Zahn-Waxler *et al.*, 2002). In particular, Immelt (2006) conducted a study involving mothers of chronically ill children and found that maternal worry and maternal perception of the impact of the child's illness on the family were the strongest predictors of poor psychosocial adjustment in the ill child. Negative parent-child interactions were also associated with poor emotional and behavioural adjustment in children with chronic medical problems (Immelt, 2006). Studies have also shown that parental stress can lead to an exacerbation of illness symptoms in children who are chronically unwell, as well as to poor treatment compliance (Hamlett *et al.*, 1992; Major, 2003; Patterson *et al.*, 1990).

### ***1.5.2 Mechanisms Underlying the Relationship between Parent and Child Well-being***

Given the nature of anxiety, it is understandable that anxious parents often display over-protective and somewhat controlling parenting styles, which may be an attempt to keep their child safe from perceived harm (MCclure *et al.*, 2001).

Given the additional health risks often faced by children who have chronic illnesses (e.g., if they do not comply with their treatment regime or lifestyle changes), it is understandable that parents often become over-protective in a desperate attempt to enhance their child's physical health and well-being (Garstein *et al.*, 2000). However, research has demonstrated that children of anxious parents are more likely to experience anxiety themselves (McClure *et al.*, 2001). Parents with high levels of anxiety might also have an excessive focus on illness-related tasks and spend less time encouraging independence in their child and less emphasis being placed on other areas of the child's life (e.g., school work, socialising, hobbies), resulting in an unhealthy balance and, potentially, reduced emotional well-being within the child (Minor *et al.*, 2006). Research also suggests that parents who perceive their child as vulnerable in some way may also be more lenient in their discipline practices, which may result in increased susceptibility to behavioural problems experienced by the child (Antshell *et al.*, 2004). Parents who are experiencing heightened levels of stress and anxiety might also be more likely to perceive daily tasks and hassles as more problematic, leading to increased emotional reactivity (Hawton *et al.*, 1989). For the child, this might seem unpredictable and chaotic, resulting in reduced emotional well-being and behavioural outbursts (Carr, 1999).

Parents who are depressed may be more likely to experience irritability in response to their child, which may increase the incidence of negativity within parent-child interactions (Tarrullo *et al.*, 1994). Research also suggests that depressed parents are more likely to selectively attend to negative aspects of their child's behaviour (Fischer, 1990). This means that they may have a lowered threshold for undesirable behaviours displayed by their child, leading to increased stress and to unhelpful parenting styles, such as punishment and criticism (Beardslee *et al.*, 1998). A focus on less desirable child behaviours, whether realistic or exaggerated, and a reduction in positive reinforcement for more desirable behaviours might also serve to maintain the presence of such problematic parent-child interactions (Carr, 1999).

Furthermore, increased demands that are placed upon parents of children who display high levels of emotional and/or behavioural problems are also likely to lead to heightened distress in parents (Anastopolous *et al.*, 1992). It, thus, seems reasonable to suggest that either of these factors may play a role in precipitating the other, with the nature of this relationship being bidirectional, in that both factors are likely to interact with one another to exacerbate existing parent-child difficulties (Morgan *et al.*, 2002).

### **1.5.3 *Automised Transactional Procedures***

Dumas (2005) proposed that, over time, certain patterns of interaction can become habitual and parents and children can become locked in negative interactions, which can serve to exacerbate the distress experienced by both parties. Dumas (2005) uses the term ‘Automised Transactional Procedures’ (ATPs) to describe the interrelated ways of thinking, feeling and behaving that can become characteristic of people who interact with one another, such as parents and their children. According to Dumas (2005) ‘once we have learned to do something automatically, the well-worn path of habit tends to become a groove, providing us with a default mode of operating that can be very difficult to override’ (p.781). Whereas regular practice of helpful communication styles between a parent and their child leads them to develop a high level of skill in the use of adaptive methods of interacting, repeatedly practiced dismissive, critical or coercive styles can become habitual in the same way. Also, Dumas (2005) proposed that since these ATPs require little or no conscious awareness, parents and their children rely more on these automised ways of coping when they are stressed, which means that less attention is directed towards what is happening in the present moment and towards finding novel solutions to their problems, thereby maintaining and exacerbating parent and child distress. Dumas (2005) further proposed that enhanced mindfulness (moment-to-moment non-judgemental awareness) in parents has the potential to reduce these ATPs and, consequently, parent and child distress.

## **1.6 Interventions for Families of Chronically Ill Children**

Given the increased risk within families of chronically ill children of emotional and behavioural problems in children and reduced psychological well-being in parents, as well as the potential interactional and perpetuating nature of these difficulties, it seems paramount that interventions are aimed at reducing the difficulties experienced by this population.

A literature review was conducted by the author in order to examine the existing evidence base for interventions aimed to enhance the well-being of parents who have children with chronic illnesses. The literature search was conducted using databases such as OVID, PsycINFO, EMBASE and Cochran and EBM reviews. Relevant articles (published between 1980 and 2008) were accessed using the following terms: child, chronic illness, physical illness, medical illness, psychological treatment, psychological intervention, psychological therapy, emotional well-being, mental health, parent, maternal, paternal, mother and father, which were entered in various combinations. Relevant articles were identified by reading through the abstracts produced. Relevant articles were also accessed through search engines such as Google Scholar and Google Books by inputting the terms detailed above. This was also used to identify the most commonly cited articles in these areas, in order to track the source of such. In addition to this the author also searched for relevant articles within the literature that had been collated by her and her field supervisor over the years of working within this specialism.

The literature review revealed a scarcity of research investigating the effectiveness of interventions aimed to alleviate the distress experienced by parents of chronically ill children. A total of five studies were identified, which fall within the following broad and somewhat overlapping categories, namely family therapy, behavioural therapy, emotional support, relaxation training and psychoeducation. Overall, the effectiveness of the interventions delivered to this population, in terms of enhancing psychological well-

being, appears to be relatively weak, with few indicating significant benefits for parents. An outline of these studies is provided in section 1.6.1.

### **1.6.1 *Outline of Existing Interventions***

Wysocki *et al.* (2000) conducted a study investigating the effectiveness of Behavioural Family Systems Therapy (BFST) for 119 families of adolescents with Type 1 diabetes. This comprised 10 sessions involving family problem-solving training, communication skills training and cognitive restructuring, as well as weekly homework assignments. Results suggested that BFST improved parent-adolescent relations and reduced diabetes-specific conflict. However, there were no significant improvements in parental or adolescent psychological well-being. The authors concluded that 'giving families general skills that improve parent-adolescent relationships does not guarantee that those skills will be applied to enhance family coping with diabetes' (p.31). In view of this, it seems that families may benefit more from developing skills that would enable them to relate differently to stressful experiences, which could be generalised to parent-child interactions as well as to other illness-related and other life stressors.

Tew *et al.*, (2002) evaluated the effectiveness of a 10-session Filial Therapy intervention with 12 parents of chronically ill children. The intervention involved teaching parents child-centred play therapy skills and aimed to reduce the distress experienced by parents in relation to their parenting role by enhancing the emotional and behavioural well-being of the child. Parents were taught how to enhance and strengthen the parent-child relationship by creating an accepting environment, in which their children felt able to express and explore their thoughts and feelings. Results of this study were promising in that they demonstrated significantly greater levels of parental acceptance toward their children's behaviour, as measured by the Porter Parental Acceptance Scale (PPAS, Porter, 1954), in comparison with the control condition (n=11). Results also demonstrated significantly fewer emotional and behavioural problems within the child. However, this



intervention failed to lead to significant reductions in parenting distress, as measured by the Parental Distress subscale of the Parenting Stress Index (Abidin, 1983).

Ireys *et al.*, (2001) also found evidence to support the effectiveness of a community-based family intervention aimed at reducing psychological distress experienced by mothers of chronically ill children. This study randomised 25 mothers to the intervention condition and 20 mothers to a control group. The intervention lasted for 15 months and involved linking parents of school-aged children with chronic illnesses with 'more experienced' parents of older children with the same condition, who provided these mothers with emotional support and advice. Results showed that, compared with mothers who received routine care, mothers in the intervention group reported significantly less anxiety following treatment ( $d=0.15$ ). However, this study did not find improvements in depressive symptoms experienced by mothers in either of the groups. The absence of a follow-up measure in this study also prevented the assessment of whether this approach resulted in sustained benefits over time. Also, since this study included only mothers, it is unclear whether this approach would also provide benefit to fathers of chronically ill children. This type of intervention might also be less accessible for parents who have children suffering from rare disorders, as it relies on the availability of parents who have an older child with the same disorder. This raises further questions regarding the availability of such support, especially given the significant time commitment required from the experienced parents, who might also be continuing to care for their own chronically ill child.

Moreover, Hernandez and Kolb (1998) randomly assigned 20 primary caregivers of children with chronic illnesses to a control condition and an intervention condition, which involved training in self-applied breathing and guided imagery relaxation techniques. Results indicated that parents reported less anxiety following the intervention, although these findings were not statistically significant. The authors interpreted these findings to suggest that further research involving a larger sample

would be required to determine whether this approach may be effective for this client group.

Satin *et al.*, (1989) also conducted a randomised controlled trial involving 32 families of adolescents with diabetes who were offered a psychoeducational intervention or routine care. In the intervention group, families (parents and adolescents) were offered information regarding the illness itself, the emotional impact of living with diabetes and helpful ways of coping. Results showed significant improvements in metabolic control, compared with controls, as well as improvements in adolescents' attitudes and self-care. However, no significant differences were found between the groups in terms of the well-being of parents.

## **1.7 Mindfulness as a Clinical Intervention**

Mindfulness interventions are being increasingly incorporated into health care settings and have the potential to enhance the well-being of parents coping with a chronically ill child (Minor *et al.*, 2006).

### **1.7.1 *Origins, Description and Purpose of Mindfulness***

Mindfulness originated in Eastern meditation practices and has been around for at least 2500 years, only relatively recently becoming an area of scientific enquiry (Hayes & Feldman, 2004). Mindfulness has its origins in Buddhism, although Western researchers and clinicians have introduced the concept into mental health treatments, independent of the religious and cultural traditions of their origins (Kabat-Zinn, 2004). Mindfulness based interventions are viewed by many as further developments of the behavioural therapy and cognitive behavioural therapy interventions that dominated the latter half of the 20<sup>th</sup> century (Hayes, 2004).

Mindfulness has been defined as 'paying attention in a particular way: on purpose, in the present moment, and non-judgementally' (Kabat-Zinn, 1994, p.4) and 'approaching one's experience with an orientation of curiosity and acceptance' (Hayes & Feldman, 2004, p.26). Mindfulness is a way of helping people to step out of 'automatic pilot', which is considered to be a mechanical way of functioning; without full awareness of what one is doing, thinking or feeling (Kabat-Zinn, 2004). Segal *et al.* (2002) talk about two modes of mind; the doing mode and the being mode, which set apart mindlessness from mindfulness. The doing mode is thought to be entered when an individual perceives a discrepancy between how things are (or how things are expected to become) and of how things are wished or ought to be. This mode of mind typically results in negative emotional states and goal-orientated cognitive and behavioural attempts to reduce this discrepancy (Segal *et al.*, 2002). In contrast, the being mode refers to accepting and allowing what is, being fully in the present moment, without trying to change anything (Segal *et al.*, 2002). Kabat-Zinn (2004) proposed that 'considerable amounts of time and energy are expended in clinging to memories, being absorbed in reverie, and regretting things that have already happened and are over.... anticipating, planning, worrying' (p.23).

Bishop (2002) proposed that mindfulness enables us to take a step back from our thoughts and feelings during stressful situations, rather than engaging in anxious worry, rumination or other negative thinking patterns that might exacerbate a cycle of stress reactivity, further negative thinking patterns and heightened emotional distress.

Various types of mindfulness exercises have been described within the literature. Many of these encourage individuals to pay attention to internal experiences, such as bodily sensations, thoughts and emotions, occurring in each moment, and others encourage attention towards aspects of the environment, for example sights and sounds (Kabat-Zinn, 1994). Although the various mindfulness practices differ somewhat in terms of procedures, they share a common goal of teaching participants to become more aware of internal stimuli (e.g., thoughts and feelings) and to change their relationship to them



(Bishop, 2002). In particular, mindfulness practices encourage participants to repeatedly identify and decenter from their internal experiences, rather than becoming caught-up in their content.

### **1.7.2 *The Attitudinal Foundation of Mindfulness Practice***

The attitude of ‘non-judgement’ is promoted during mindfulness practices. That is, phenomena that enter awareness, including cognitions, emotions and sensations, are observed carefully without judging them or acting on them in any way (Baer, 2003). According to Kabat-Zinn (2004), when people begin practising mindfulness, they become aware that judgements tend to preoccupy their minds. The habit of categorising and judging experience is thought to lock us into automatic, mechanical reactions (Kabat-Zinn, 2004), or as Dumas (2005) termed, ATPs. Linehan (1993) suggested that non-judgemental observation and description enables people to become more aware of the consequences of their behaviours, which may lead to individuals adopting new, more helpful, actions and reactions. Mindfulness practices cultivate what has been termed ‘the beginner’s mind...a mind that is willing to see everything as it is for the first time’ (Kabat-Zinn, 2004, p.35). The idea is to free ourselves from our expectations, based on our past experiences, and to open up a range of unique possibilities in our encounters with the world.

‘Acceptance’ is also a central attitude in the practice of mindfulness, which is cultivated by taking each moment as it comes and being with it fully and without defence (Hayes, 1994; Kabat-Zinn, 2004). Often people tend to try to escape or avoid unpleasant thoughts, feelings or bodily sensations (experiential avoidance), which can have undesirable consequences in that these phenomena tend to come back even stronger (Baer, 2003). Segal *et al.* (2002) proposed that ‘one way to relate skilfully to unpleasant experiences is to register that they are here and allow them to be as they are in this moment and simply to hold them in awareness...letting be... in contrast to automatically reacting to these thoughts or emotions’ (p.225). This aims to encourage individuals to

come to terms with things as they are and to begin to accept them, rather than expending energy wishing or thinking about how things could be different (Kabat-Zinn, 2004). The practice of mindfulness skills aims to improve participants' ability to tolerate negative emotional states and to cope with them more effectively (Baer, 2003).

Mindfulness practices also enable people to develop the skill of 'letting-go' of thoughts, feelings, and bodily sensations. Letting-go is proposed to be the key skill in preventing individuals from getting into and in enabling them to step out of unhelpful cycles of negative cognitions and emotions (Segal *et al.*, 2002). According to Kabat-Zinn (1990) 'when we start paying attention to our inner experience, we rapidly discover that there are certain thoughts and feelings and situations that the mind seems to want to hold on to... similarly there are many thoughts and feelings and experiences that we try to get rid of or to prevent and protect ourselves from having because they are unpleasant and painful and frightening' (p.39). In sum, mindfulness practices enable individuals to become more skilled at recognising that their mind has wandered and to adopt an attitude of curiosity to one's thoughts or feelings (from a decentered stance), without pursuing things any further, and then letting-go.

## **1.8 Mindfulness Based Treatment Approaches**

Whilst it is beyond the scope of this manuscript to review the full range of mindfulness-related treatment approaches, a brief description of Mindfulness Based Stress Reduction (Kabat-Zinn, 1982), Mindfulness Based Cognitive Therapy (Segal *et al.*, 2002) and Acceptance and Commitment Therapy (Hayes *et al.*, 1999) will be presented, along with a summary of the empirical literature relating to each approach.

### **1.8.1 Mindfulness Based Stress Reduction**

Mindfulness Based Stress Reduction (MBSR), initially developed by Kabat-Zinn (1982; 1990) has been cited most frequently within the literature. It was first developed in a behavioural medicine setting, for populations with a wide range of chronic pain and

stress-related disorders, as a group-based self-regulation approach to stress reduction (Kabat-Zinn, 1990). MBSR courses most often last for eight-weeks (which was initially designed to fit in with the American vacation period), and consist of up to 30 participants, who meet weekly for approximately two hours. Some courses also involve an all-day intensive session, which is usually introduced in the sixth week (Baer, 2003). The format is largely skill based and psychoeducational. The weekly sessions consist of instruction and practice of various mindfulness exercises, as well as discussions of stress and coping. A key feature of the course is the 45 minutes of home-based practice that participants are required to engage in, each day, for the duration of the course.

MBSR courses typically include a variety of mindfulness practices including: the body scan, mindfulness of breathing, movement practices (e.g., stretching and walking), as well as practices involving other everyday activities, such as standing, sounds, eating and drinking (Baer, 2003). For each practice, participants are encouraged to, as best they can, focus their attention on the target of the observation in each moment, whether it be breathing or bodily sensations. Participants are instructed that when emotions, sensations or cognitions arise, to try to take a stance of curiosity towards them, rather than getting caught-up in judging them as good or bad. It is instructed that, when participants become aware that their minds have wandered into, for example, thoughts, memories or fantasies, to briefly note the nature or content of these internal experiences and then, as soon as possible, to return their attention back to the present moment, to the object of the practice (Baer, 2003). It is thought that the repeated practice of mindfulness, over the duration of the course, will enable participants to generalise these skills to internal experiences that arise within everyday life (Kabat-Zinn, 2004).

MBSR courses have demonstrated effectiveness in treating a variety of problematic conditions, including stress, anxiety, depression and eating disorders (Baer, 2003; Bishop, 2002). This approach has also proven to be successful in treating a variety of

physical health conditions, including chronic pain and skin clearing in psoriasis (Baer, 2003; Kabat-Zinn *et al.*, 1998).

### **1.8.2 Mindfulness Based Cognitive Therapy**

Segal *et al.* (2002) developed an eight-week, group-based, Mindfulness Based Cognitive Therapy (MBCT) intervention, based largely on Kabat-Zinn's (1990) MBSR course. In addition to the components of MBSR described above, MBCT incorporates elements of cognitive therapy that promotes a detached or decentered view of one's thoughts, emotions and bodily sensations. In particular, the course involves didactic teaching on depression, aimed at educating participants about the relationships between thoughts, feelings and behaviour, which can serve to maintain and exacerbate distress. MBCT courses also typically include various in-session and home-based exercises to help socialise participants to these ideas (Segal *et al.*, 2002).

MBCT was initially designed to prevent depressive relapse by enabling participants with a history of depression to observe their thoughts and feelings non-judgementally and as if they are simply mental events that come and go in the mind, rather than true reflections of reality (Segal *et al.*, 2002). Therefore, the cognitive components of MBCT, coupled with the practice of mindfulness, are thought to reduce individuals' reactivity to their negative thoughts or emotions (Coffman *et al.*, 2006). MBCT was aimed to prevent the escalation of negative thoughts into ruminative patterns, during periods of low mood, in order to reduce the likelihood of a new depressive episode (Segal *et al.*, 2002).

MBCT has been shown to effectively treat depressive relapse in medication-resistant patients (Teasdale *et al.*, 2000). As a consequence, MBCT has been recommended by the National Institute of Health and Clinical Excellence (NICE; 2004) for treating depressive relapse in adults within healthcare settings. Research has also demonstrated that MBCT may be helpful for treating active depression and anxiety (e.g., Finucane & Mercer, 2006).

### **1.8.3 Acceptance and Commitment Therapy**

Acceptance and Commitment Therapy (ACT; Hayes *et al.*, 1999) is a mindfulness-based behavioural therapy, which has both similar and distinctive aspects to other mindfulness-based approaches. A central concept in ACT is 'experiential avoidance'. This is an unwillingness to experience negative internal phenomena, such as feelings, thoughts and sensations. This is thought to lead to counterproductive attempts to avoid or eliminate these experiences, including thought suppression and situational avoidance, which can interfere with a person's ability to lead a value-driven and fulfilling life (Hayes *et al.*, 1999). Similar to MBSR and MBCT, ACT places emphasis on the development of mindfulness skills, although differs from other mindfulness-based interventions in the explicit attention it pays to a person's most deeply held life values and to the behaviour changes that may be necessary to pursue these (Hayes *et al.*, 1999). Hayes *et al.* (2006) described values as 'chosen qualities of purposive action that can never be obtained as an object but can be instantiated moment by moment' (p.9) and suggested that they may fall within various domains, including family, career and spirituality. For example, an individual might have a personal life value 'to be a good husband/wife' yet might find that their behaviour does not lead them in this direction (e.g., due to excessive work commitments or due to excessive amounts of time being directed towards caring for their ill child). ACT helps people to identify their personal life values, which people often lose track of during difficult times, and to commit to behaviours that lead them in these directions, in order to reduce the distress associated with this discrepancy.

Although ACT is a relatively recent approach, there is a growing body of evidence that demonstrates its effectiveness in treating a variety of clinical problems, including stress, anxiety and depression (e.g., Bond & Bunce, 2000; Forman *et al.*, 2007).

## **1.9 Mindfulness-Based Interventions for Parents**

Based on the demonstrated success of mindfulness-based interventions in enhancing well-being in other highly distressed groups (Baer, 2003; Bishop, 2002), it would be



reasonable to assume that such an approach would be beneficial for distressed parents who have children with chronic illnesses. Various aspects of mindfulness interventions might also make these approaches particularly suitable for this population.

Mindfulness training has the potential to enable parents to break free from cognitive styles that are common during periods of difficulty, for example, ruminative thinking, during periods of chronic sorrow, or future-orientated worry, during periods of illness-related uncertainty. Mindfulness also has the potential to cultivate an attitude of acceptance within parents of chronically ill children, who often struggle to come to terms with their child's illness (Bonner *et al.*, 2005). Also, according to Singh *et al.* (2007) mindful parents may be more able to respond to difficult child behaviours in alternative ways, without the limitations imposed by past conditioning. By stepping out of these well-worn grooves of interactional patterns (Dumas, 2005), this has the potential to benefit the parent-child interaction, thereby enhancing the well-being of both the parent and the child.

Moreover, Heinzer (1998) suggested that parents caring for chronically ill children often find themselves excessively directing their energies towards the illness-orientated needs of their child and, in the process, neglect their own health and wellbeing. Specific aspects of ACT (Hayes *et al.*, 1999), thus, have the potential to help parents develop a healthier balance between the tasks associated with caring for their child and their own chosen life values, which often represent important self-care behaviours. These might include involvement in friendships and relationships with other family members (including other children and partners), participation in hobbies, sports or spirituality. Although behaviours such as these have long been established to serve to enhance one's psychological well-being (Cohen & Wills, 1985; Taylor *et al.*, 1985), there is now a growing body of research to suggest that helping people to direct their behaviours towards their chosen life values can enhance their current psychological well-being and reduce psychological distress, as well as acting as a buffer for when future problems arise (Bar, 2006; Eifert & Forsyth, 2005; Forman *et al.*, 2007; Hayes *et al.*, 1999).

### 1.9.1 *Existing Research on the Effectiveness of Mindfulness Approaches with Parents*

Singh *et al.* (2006) investigated the effectiveness of a 12-week mindfulness course for three mothers of children with autism. Results demonstrated that the mindfulness course increased participants' satisfaction with various aspects of their parenting role, including their parenting skills, interactions with their children and with their child's behaviour. Although these are promising results, the small sample size limits the generalisability of these findings and prevented the authors from conducting statistical analysis on the data.

Minor *et al.* (2006) also conducted a study to investigate the effectiveness of an eight-week MBSR course aimed to enhance the psychological well-being of caregivers of children with chronic conditions, including those pertaining to physical health, mental health and learning disabilities. This study was conducted over a 3 year period and comprised seven separate MBSR groups involving a total of 44 participants. Pre- and post-treatment comparisons indicated an overall reduction in parental stress symptoms of 32 percent ( $p < .001$ ) and in parental mood disturbance of 56 percent ( $p < .001$ ).

These are promising findings, which suggest that MBSR may be beneficial for parents of children with chronic conditions. However, as the authors did not report the proportions of parents within each category, it is unclear whether each group was equally represented. Also, there were no comparisons made between each of these groups, in terms of treatment gains, which makes it difficult to determine whether the intervention was equally as effective for parents who have chronically ill children as for parents of children with learning disabilities or mental health problems.

Although parents of children with different chronic conditions might experience a range of common challenges, including accepting the child's condition, managing the child's condition on a daily basis and meeting the child's developmental needs (Canam, 1993), it is likely that there are specific stressors that are faced by parents in each of these

groups. Perrin *et al.* (1993) proposed that ‘the personal and social consequences of mental health problems and learning disabilities differ from those experienced by children with illnesses traditionally considered physical’ (p.790). For example, parents of chronically ill children might be exposed, more often, to the threat of a progression of their child’s illness or to the possibility of death, as a result of the changeable nature of their child’s chronic illness.

Moreover, the study by Minor *et al.* (2006) did not include a follow-up measure, which prevented investigation of whether the observed improvements were maintained beyond the course. The authors also reported that a number of potential participants did not take part in the MBSR course due to the eight-week time commitment and the home study required, although the authors did not report the specific number of potential participants that this referred to. Finally, this study did not include a measure of mindfulness in order to explore whether parents did indeed become more mindful over the course of the study.

### **1.10 Aims of Current Study**

The current study aims to extend the findings obtained by Minor *et al.* (2006), in order to identify whether a mindfulness-based course, tailored specifically to the needs of parents who have chronically ill children, is effective in enhancing mindfulness and improving emotional wellbeing. The study also aims to explore whether the intervention improves participants’ perceptions of the difficulties associated with their role as parents and of the well-being of their child.

To the author’s knowledge, there have been no MBSR courses designed specifically for parents of chronically ill children. To this end, the course involved in the current study was based primarily on MBSR (Kabat-Zinn, 1982; 1990) and included components of MBCT (Segal *et al.*, 2002) and ACT (Hayes *et al.*, 1999). As suggested by Mace (2007), ‘there is a growing tendency for treatment packages to be designed that combine



elements of, say, MBSR with exercises from acceptance and commitment therapy' (p.152).

In order to make the intervention more accessible to parents of chronically ill children, for whom existing demands are often high, the current study reduced the duration of the course to six-weeks and substituted the typical 45 minutes daily practice for a shorter 30 minutes. This modification is explained in more detail in the method section of this manuscript. In addition to this, a follow-up measure was included to determine whether any improvements were maintained over time.

### **1.11 Hypotheses**

The current pilot study seeks to examine the following hypotheses in relation to a mindfulness course designed specifically for parents of chronically ill children.

#### **Principal Hypotheses**

1. Participants who take part in the MBSR course will report higher levels of mindfulness post-treatment and at 3-months follow-up than at pre-treatment.
2. Participants taking part in the MBSR course will report lower levels of anxiety and depression post-treatment and at 3-months follow-up than at pre-treatment.

#### **Secondary Hypotheses**

3. Participants taking part in the MBSR course will report less difficulty associated with parenting post-treatment and at 3-months follow-up than at pre-treatment.
4. Participants who take part in the MBSR course will perceive improvements in their child's wellbeing post-treatment and at 3-months follow-up relative to pre-treatment.

## **Chapter 2: Methodology**

### **Overview**

This study investigated the effectiveness of a six-week Mindfulness Based Stress Reduction (MBSR) course, designed specifically for parents of children with chronic illnesses.

### **2.1 Design**

It was initially intended that a waiting-list control group design would be implemented in the current study. However, due to slow recruitment, a within subjects repeated measures design was employed: that is, all participants were delivered the MBSR intervention and tested on all measures, at various time points (pre-treatment, immediately post-treatment and three months post-treatment). Participants, thus, served as their own controls. The strengths and limitations of this design are explored within the discussion section of this manuscript.

### **2.2 Participants**

The sample comprised a group of parents of children who had various chronic illnesses and who were aged between 3 and 12. These parents also had clinically significant levels of anxiety and/or depression.

### **2.3 Inclusion and Exclusion Criteria**

#### **2.3.1 Inclusion Criteria**

All participants were required to have:

- A score of 8 or above on the anxiety and/or depression subscales of the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983).
- At least one child aged between 3 and 12 years with a chronic illness, who was an outpatient at Royal Aberdeen Children's Hospital. The age range specified for inclusion in the current study was determined by the criteria of the Child and Family Mental Health Service within which the principal researcher worked.

### **2.3.2 Exclusion Criteria**

Given that the intervention relied on group practices and group-level discussions, individuals were excluded from the study if they were judged to have potential difficulty participating in a group setting, specifically, if they were suffering from a psychotic episode, a personality disorder or co-morbid substance abuse. These factors have been identified to interfere with an individual's ability to benefit from group therapy and to be potentially detrimental to group processes and drop-out rates (Yalom, 1985).

## **2.4 Procedure**

### **2.4.1 Recruitment Process**

Extensive efforts were made to recruit participants. With the permission of various service managers and heads of departments, posters (Appendix 1) and leaflets (Appendix 2) were displayed in all the key locations throughout Royal Aberdeen Children's Hospital, including: the Medical Ward; the Surgical Ward; the parents' lounge; all four outpatient clinics; the Day Hospital Ward; the Occupational Therapy Department; the Physiotherapy Department; and the cafeteria. Posters and leaflets were also displayed within ten General Practices in disperse locations around Aberdeen city and at the local Carers' Centre. The leaflets detailed information regarding the course, background information on MBSR and sources for further reading. The leaflets also provided contact details for the principal researcher, to enable potential participants to inquire further about the course or to register their interest.

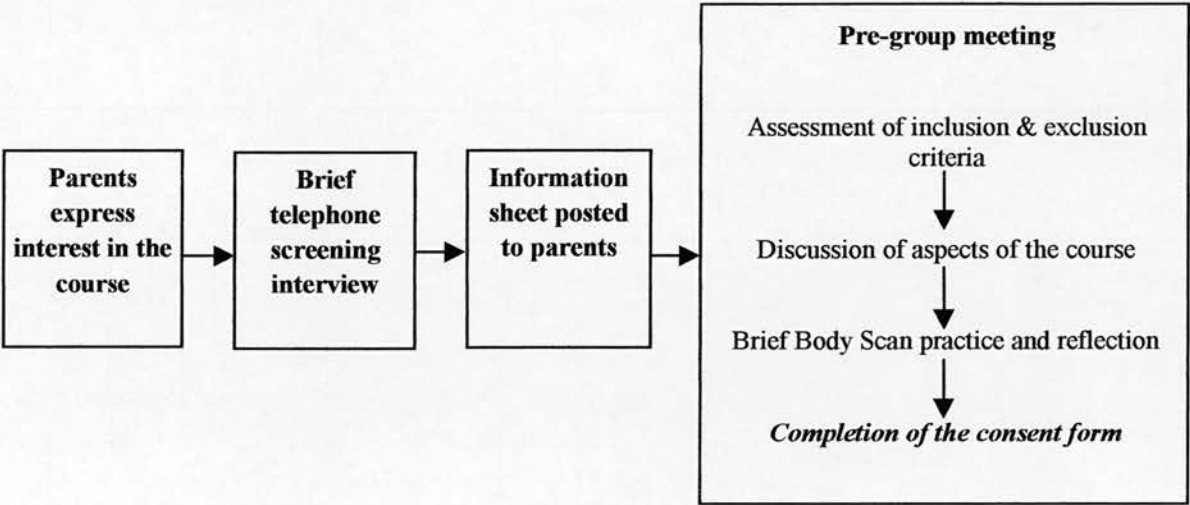
Further efforts were made by the principal researcher to raise awareness of the study, including:

- Meetings with specialist nurses and medical and surgical consultants.
- Placing a small advertisement in the local press, on four occasions, via the local NHS Corporate Communications Office (CCO).
- Releasing a brief story about the study to the local press (via the NHS CCO).
- Disseminating information regarding the study to local support groups for parents of children with chronic medical problems.

Once parents had registered their interest in the course, they were invited to attend a 60 minute pre-group meeting with the principal researcher. Prior to the meeting, a copy of the information sheet (Appendix 3) was posted to potential participants, in order to provide sufficient time for them to read the material and to generate questions that could be discussed during the meeting. During the meeting, parents were asked about their hopes and expectations of the course, in order to identify and clarify any misunderstandings. This was followed by an exploration of the inclusion and exclusion criteria (detailed in section 2.3) and included administering the Hospital Anxiety and Depression Scale (HADS; Zigmond and Snaith, 1983). Parents who met the study requirements were verbally provided with information about various aspects of the research project including the aims of the study, the assessment process and details of the MBSR course. This was to ensure that individuals had an accurate understanding of what their participation in the study would entail.

The principal researcher particularly emphasised the substantial time commitment of participating in the study (weekly group meetings & daily home practice) to ensure parents were provided with an opportunity to opt-out should they perceive the course-requirements to be too high. This was considered especially important in view of the well documented, wide-ranging, demands upon parents of children with chronic illness (Perkin *et al.*, 2007). This was also an important aspect of the recruitment process, considering it is not infrequent that MBSR group members report difficulty finding time to engage in the home-based practice, despite this being a central feature of mindfulness-based interventions (Segal *et al.*, 2002). Issues pertaining to the confidentiality of information gathered and the rights of participants to withdraw from the study at any point were also discussed. All of these issues were also covered in the information sheet, which participants were able to retain. If parents were satisfied with the issues discussed, a brief fifteen minute mindfulness practice was conducted by the principal researcher. This aimed to provide potential participants with greater insight into the nature of mindfulness practices. A body-scan practice (described in section 2.5.5) was used in this instance as it is considered to be one of the most accessible mindfulness practices to

people who have had little or no experience in this area (Kabat-Zinn, 2004). Participants were subsequently given the opportunity to reflect on their experiences during the practice and to ask any questions that arose. Parents who continued to express interest were then presented with a consent form to sign (Appendix 4). A diagrammatic representation of the sequence of events leading to participants providing consent is presented in Figure 2.1.



**Figure 2.1:** Sequence of events leading to parents giving consent to participate

#### 2.4.2 Assessment Procedure

Prior to the group commencing, participants were sent the demographic questionnaire, in order to allow the researcher to gather relevant background information. Participants were also asked to complete six additional questionnaires at three time points (pre-treatment, post-treatment & three months post-treatment). These questionnaires measured: mindfulness (the Cognitive & Affective Mindfulness Scale- Revised & the Acceptance & Action Questionnaire- Revised); psychological wellbeing (the Beck Anxiety Inventory & the Beck Depression Inventory- II); difficulties associated with parenting (Parenting Stress Index– Short Form); and parents’ perceptions of their child’s well-being (the Strengths & Difficulties Questionnaire). Immediately following the

course, participants were also asked to complete a Course Evaluation Form. The description and psychometric properties (if applicable) of each measure are outlined in section 2.6. The questionnaires administered pre-treatment and at three months following treatment were posted to participant's home addresses, whereas the questionnaires administered post-treatment were handed to participants at the end of the final group meeting. All questionnaire packs were provided with a stamped addressed envelope for their return.

## **2.5 Mindfulness Based Stress Reduction (MBSR) Course**

### **2.5.1 *Practical Aspects***

The group sessions were held in one of the seminar rooms at the Royal Aberdeen Children's Hospital. The room was of sufficient size to enable mindfulness practices that involved participants lying on mats on the floor. Yoga mats were provided for use during such practices. The room was carpeted, comfortably warm and located in a quiet area of the hospital. The group sessions were held from 6.30pm to 8.30pm every Tuesday.

### **2.5.2 *Course Design***

The MBSR course involved in the current study was specially designed for anxious, stressed and depressed parents of chronically ill children. The course was primarily based on the MBSR course developed by Kabat-Zinn (1982, 1990), including elements such as the weekly-group meetings; various mindfulness practices (both as homework & within each session); group-level reflections on these practices; discussions surrounding the different principles of mindfulness and the nature and impact of stress; as well as the inclusion of pleasant and unpleasant events monitoring.

In order to specifically target depressive symptomatology, various key elements of MBCT (Segal et al, 2002) were incorporated into the course, namely educational components based on the principles of cognitive therapy (CT) and a relapse-prevention plan (each aspect of the course is described in more detail in section 2.5.5). Despite the



inclusion of the key elements of MBCT within the current study, the decision was made to use the title of a MBSR course, since Mindfulness Based *Stress Reduction* was considered to be more accessible, than Mindfulness Based *Cognitive Therapy*, to people without prior knowledge of these approaches. Also, as participants were required to essentially self-select, the former term was considered to be more likely to attract the attention of distressed parents. There were also aspects of MBCT that were not included in the current study (e.g., the use of thought monitoring questionnaires; teaching around the diagnostic criteria for depression; and exercises and discussions regarding alternative interpretations for depressogenic thoughts). Educational components on anxiety, drawing on the themes of cognitive therapy, were also included, which were not originally included in MBCT courses, since these were designed specifically for treating depressive relapse.

A small component derived from Acceptance and Commitment Therapy (Hayes et al, 1999) was also included in the course, in order to help participants recognise their deeply held life values and potential discrepancies between these and the ways in which they were living their lives (section 1.9 outlines the rationale for this approach with parents of chronically ill children).

The course was also shortened from the standard eight-week MBSR and MBCT courses (Baer, 2006; Segal *et al.*, 2002) to make it more accessible to busy parents. This involved reducing the length of the course from the standard eight week duration to six weeks and the home-based practice from 45 minutes per day, involved in standard MBSR and MBCT courses (Baer, 2006), to 30 minutes daily. Six-week MBSR courses have been found to effectively treat symptoms of anxiety and depression in patients with a binge eating disorder, as well as to significantly reduce binge eating behaviours (Kristeller & Hallett, 1999). Courses of this length have also been demonstrated to lead to significant improvements in mindfulness and psychological distress, in a sample of patients with psychosis (Chadwick *et al.*, 2005).

### 2.5.3 Course Delivery

The course was run by the principal researcher, who received standard training in mindfulness, and a consultant health psychologist (the principal researcher's field supervisor), who received standard training in mindfulness and teacher training level instruction, as well as monthly supervision from the Centre of Mindfulness Based Research and Practice, at Bangor University in Wales.

A manual was developed specifically for the course and presented to all participants at the beginning of the first group meeting (Appendix 5). The central attitudes of mindfulness (see section 1.7.2) proposed by Kabat-Zinn (2004) were encouraged and reinforced by the facilitators throughout each mindfulness practice and during the group-based discussions. The principle of learning through experience and the importance of regular home-based practice, a central component of mindfulness-based courses (Kabat-Zinn, 2004; Segal *et al.*, 2002), were reinforced throughout the six weeks.

Participants were instructed to carry out home-based practices, every day, for the duration of the course (with the exception of the days that the meetings were held). Home-based practices generally lasted for 30 minutes, although towards the end of the course shorter practices were introduced and it was participants' choice whether they engaged in these or continued with the longer practices (Table 2.1).

Participants were provided with a CD each week that contained the mindfulness practice(s) designated as homework. They were asked to record, in a practice diary (Appendix 6), the type, number and length of practices carried out each day. This was incorporated into the current study to provide an estimate of the amount of practice participants were engaging in over the duration of the course. Participants were also advised that they could write down any comments that arose from the home practices, which could (if they wished) be discussed during the group-level reflections on home-practice.

#### 2.5.4 Group Sessions- General Structure

The group sessions followed the same general structure, as detailed below.

- a. Participants were guided through a ten minute mindfulness of breathing practice
- b. Group-level reflection on home-based mindfulness practices and course tasks
- c. Facilitator-led, group-based, discussion regarding a specific educational topic
- d. Participants were guided through the principal mindfulness practice(s)
- e. Group-level inquiry of participants' experiences of the mindfulness practice
- f. Explanation of the following week's home-practice and course tasks

Session one differed slightly in that the ten minute mindfulness of breathing practice and reflections on home-based mindfulness practice were substituted with tasks that were designed to set the scene for the course to progress. These included introductions among participants and the course facilitators, and participants separating into pairs to discuss what they intended to give up in their daily lives in order to make time for the home-practice, and to identify what they had hoped to gain from the course. Ground rules were also established and agreed within the group. The remainder of the first session followed the same general structure as other sessions.

The flow of sessions 2 to 6 was as follows;



The rationale behind each element of the weekly-group sessions is detailed in section 2.5.5. Although certain elements remained consistent each week, including the brief ten-minute mindfulness of breathing practice, time set-aside for discussions regarding the home-based practice and group-level inquiry of the principal in-session mindfulness practice (elements a, b & e), the specific nature of the remaining elements (c, d & f) changed. Therefore, a different educational topic was discussed each week, the specific nature of the principal mindfulness practices changed most weeks and the home-practice

and course tasks differed each week. A brief outline of the weekly-specific elements of the course is presented in Table 2.1. A more detailed description of the content of each session is presented within the course manual (Appendix 5).

**Table 2.1:** Outline of Weekly-specific: Educational Components, Mindfulness Practices & Home Practice instructions.

Week	Educational Theme	Principal Mindfulness Practice(s)	Home Based Practice Instruction
1	Introduction to the different attitudes of mindfulness (MBSR)	<ul style="list-style-type: none"> <li>45 minute Body Scan practice'''</li> </ul>	<ul style="list-style-type: none"> <li>30 minute Body Scan practice daily</li> </ul>
2	Introduction to the relationship between our thoughts, feelings and behaviour (MBCT)	<ul style="list-style-type: none"> <li>45 minute Body Scan practice</li> </ul>	<ul style="list-style-type: none"> <li>30 minute Body Scan practice daily</li> <li>Carry-out one daily activity mindfully</li> </ul>
3	Nature of stress and anxiety and the role for mindfulness (adaptation of MBCT)	<ul style="list-style-type: none"> <li>30 minutes Mindfulness of Breathing practice</li> </ul>	<ul style="list-style-type: none"> <li>30 minute Mindfulness of Breathing practice daily</li> <li>Complete the pleasant and unpleasant events diary</li> <li>Carry-out one daily activity mindfully</li> </ul>
4	Nature of depression and the role for mindfulness (MBCT)	<ul style="list-style-type: none"> <li>3 minute Coping Space practice</li> <li>20 minute Mindfulness of Walking practice</li> </ul>	<ul style="list-style-type: none"> <li>30 minute Mindfulness of Breathing practice daily</li> <li>Carry-out one daily activity mindfully</li> <li>Carry-out the Coping Space practice during periods of distress</li> </ul>
5	Life values (ACT)	<ul style="list-style-type: none"> <li>30 minute Mindfulness of Body, Thoughts and Sounds practice</li> </ul>	<ul style="list-style-type: none"> <li>Self selection of any practice covered over the course- at least one to be carried-out each day</li> <li>Coping Space practice during periods of distress</li> </ul>
6	Relapse prevention and incorporating mindfulness into daily life (MBCT)	<ul style="list-style-type: none"> <li>Brief practices including: Mindfulness of Breathing; Mindfulness of Sounds; Mindfulness of Walking &amp; Coping Space</li> </ul>	

### 2.5.5 *Rationale*

#### a. *Ten-Minute Mindfulness Practice*

The initial ten-minute practice was conducted to orientate participants to the business of the course and to enable participants to shift from the doing to the being mode (see section 1.7.1).

#### b. *Group-level reflection on home-based mindfulness practices and any other course tasks*

Following the short practice, an opportunity was provided for participants to discuss their experiences of the home-based practice over the past week. This is viewed as an important aspect of MBSR and MBCT courses because there are many difficulties that people might experience with home-based practices (Segal *et al.*, 2002). Common difficulties include;

- Feeling that you can't find sufficient time to carry-out the home-based practice
- Getting bored or becoming irritated with the instructions.
- Falling asleep
- Feeling as if you are doing it incorrectly (e.g., 'I am trying my best and I still don't think I'm getting it')
- Reconnecting with uncomfortable or avoided emotion (e.g., 'I just got too upset')
- Finding that the mind keeps wandering

Many of these difficulties are conceptualised as representing typical problems that people experience in daily life (e.g., reconnecting with uncomfortable or avoided emotions, mind wandering, getting bored or becoming irritated). Therefore, it is considered important to provide participants with an opportunity to express any difficulties that they might be experiencing and for the group facilitator to encourage them to acknowledge and become curious about their experiences. This is akin to awareness-raising in cognitive therapy and involves participants moving toward rather than away from any uncomfortable experiences. This process also provides an



opportunity for the facilitators and other group members to offer some potential solutions to practical difficulties that may arise (e.g., if falling asleep is a problem then to think about what might be the best time of day to carry-out the practices).

*c. Educational Components*

*Attitudes of Mindfulness*

Participants were initially introduced to the different attitudes of mindfulness, including present focus, acceptance, non-judgment & letting-go (section 1.7.1). This aimed to introduce participants to the nature of the course and the mindfulness practices to follow. Different attitudes towards approaching the course were also discussed. Participants were discouraged from approaching the course either believing it definitely wouldn't work or believing that it would be a solution to all of their problems. Rather, they were advised to be open, constructively critical, and to try to immerse themselves in the course for the six weeks, to see what happens. This is generally the recommended approach to mindfulness-based programmes. According to Kabat-Zinn (2004), 'consciously cultivating certain attitudes can be very helpful in getting the most out of the process' (p. 32).

*Teaching Components Consistent with MBCT*

Given that many parents who have chronically ill children experience significant levels of stress, anxiety and depression, teaching sessions were directed at enhancing participants' awareness of the factors that can serve to perpetuate and maintain such difficulties. Therefore, drawing on aspects of MBCT (Segal *et al.*, 2002), a mindfulness based cognitive-behavioural approach to discussing various topics was adopted. The educational components were initially focused on linking thoughts, feelings and behaviours. This was introduced using the classic scenario included in standard MBCT courses (drawn from cognitive therapy). This involves imagining that you are walking down the street, waving at someone you know, but receiving no response from that person (session 2). Participants were asked to generate a range of responses they might have to this situation, including thoughts, feelings and behaviours. Contributions to this



discussion were then used to explain and illustrate the ABC model, in which the situation (A) leads to a thought or interpretation (B), that leads to a feeling C). This was intended to demonstrate that different thoughts can lead to different emotions and that thoughts are not facts. The discussion then progressed towards the idea that, because our thoughts can have a powerful influence on our emotions, it is important that we become aware of them, which can be developed through the practice of mindfulness.

Subsequent sessions built upon this foundation and essentially covered the cognitive behavioural models of stress/ anxiety (session 3) and depression (session 4). Therefore, the powerful role of our thinking, in determining how we feel and behave, was discussed. This aimed to encourage participants to raise awareness of their internal processes and to begin to take a decentered stance towards them. The message conveyed was that thoughts are not facts, and that many of the cognitive events that we can become caught-up with are relatively unimportant or unhelpful (Segal *et al.*, 2002).

### *Life Values*

An Acceptance and Commitment Therapy (ACT) exercise was introduced to explore the extent to which participants held ten common values (e.g., parenting, friendship, spirituality, career/employment) and the extent to which they were present in their lives (see pages 25-26 of the course manual in Appendix 5). Therefore, participants were essentially encouraged to explore, in a structured way, the extent to which they were living their lives in accordance with their values. Participants were then encouraged to think about and plan possible ways in which they may begin to move towards their valued life directions. This small component of ACT complemented the aims and approach of the course because, explicitly, it assumes that one can live a fulfilling life in the presence of emotional pain and participants were facing chronic, unchangeable, adversity, of which the outcome was largely out of their control (the rationale for this approach with parents of chronically ill children is outlined in section 1.9).

### *Relapse Prevention*

Since in the future, participants within this study would undoubtedly experience events (whether related to their child or to other aspects of their lives), that would cause emotional difficulties, a teaching component (consistent with MBCT), was introduced in session six that focused on relapse prevention strategies (Segal *et al.*, 2002). This involved helping participants to reflect on their experiences over the past five weeks and to identify their own personal warning signs of increasing emotional difficulties, to note these, and to decide how best to manage these if or when they occur. To this end, some time was spent discussing with participants various helpful (e.g., mindfulness, exercise & seeking support) and unhelpful (e.g., avoidance, suppression) ways of managing such emotions and all participants were encouraged to generate their own relapse-prevention script (Segal *et al.*, 2002). This also involved helping participants identify how they could incorporate mindfulness practices into their daily lives as a form of self-care.

#### *d. Principal Mindfulness Practices*

The main in-session practices were included in order to introduce participants to different types of mindfulness practices and to provide opportunities for various barriers to arise, which could then be discussed within the group. A variety of practices was introduced in order to help participants to develop different ways of being present within their daily lives.

The Body Scan was the first practice introduced and involves attention being directed sequentially to different areas of the body (from the toes to the head) over a period of 30-45 minutes. The body scan is considered to be an important starting point as it encourages a greater awareness of the body, which is helpful when learning how to recognise and then deal with negative emotions (which tend to manifest within the body). According to Segal *et al.* (2002) 'feedback on how the body feels is often an integral part of the loop that sustains old habits of thinking and feeling' (p. 110). In addition to becoming more aware of negative emotional states as they arise, by focusing on the body, it is proposed that we become more able to step back from old habits of

thinking (e.g., ruminating or worrying), which often serve to maintain distress (Kabat-Zinn, 2004). The body scan is also the practice that contains the largest amount of instructions; the least amount of silence, and is the most cognitively complex, thereby considered the easiest of the longer mindfulness practices for beginners since it provides less opportunities for the mind to wander.

The Mindfulness of Breathing practice involved directing participants' attention towards the sensations of breathing in various parts of the body. As is usual practice, participants were encouraged not to change their breathing in any way, rather to merely observe it. Invitations to focus attention on sensations in the mouth, throat, chest, stomach and any other salient places were made. Some time was set aside within this practice to focus on sounds within the environment, which again is standard practice. This can be a difficult practice, partly because of the increased silence compared to the body scan and also because the task is more repetitive and less cognitively stimulating.

Mindfulness of Walking involved encouraging awareness of sensations within the body, which might change or stay the same from one step to the next. These sensations would commonly be most apparent in the feet and lower legs, but participants were directed to widen their focus to other aspects of their body and posture. Participants were instructed to walk very slowly, typically taking steps less than half the usual length. Initially, this exercise took place within the seminar room and then out in the corridor and around the waiting area, as participants were encouraged to walk nearer to their usual pace. The mindfulness of walking practice is part of a series of explicit attempts to bring mindfulness to daily activities. In addition, this practice can be accessible for those who struggle somewhat with the more contemplative and less physical practices such as body scan and mindfulness of breathing.

Mindfulness of Body, Thoughts and Sounds involved guiding participants initially through a brief (10-15 minute) body scan practice and then progressing to focusing on whatever came up in their minds, whether this be thoughts, images or words.



Participants were encouraged to view these cognitions from a decentered stance, without getting caught up in their content. Metaphors such as '*watch your thoughts as if they are on a stage, while you are in the audience*', were used. Finally, the practice progressed to focusing on any sounds that arose and this part of the practice involved very few words being spoken.

Finally, a brief 3-minute coping space practice (consistent with MBCT) was introduced into the course to allow mindfulness skills learned in formal mindfulness practice to be generalised to daily life. The brevity of this practice also enables individuals to use it to step-out of automatic pilot at any time, even during a hectic day, to re-establish awareness of the present moment. Participants were first encouraged to focus their awareness on the range of internal experiences (bodily sensations, thoughts or emotional states) currently occurring, asking themselves '*What is my experience right now*'. A stance of non-judgemental acceptance was encouraged, thereby not pushing away or suppressing experiences, even if they are unpleasant and unwanted, but rather acknowledging them all. The second step was to focus attention on the sensations and movements of breathing, before expanding awareness to the body as a whole, including posture and facial expression, and to notice sensations that are present, again with the stance of non-judgement and acceptance. The coping space was introduced in week three and participants were asked to practice it several times per day for the remainder of the course. Initially participants were asked to schedule regular times to practice it and were subsequently encouraged to use this practice whenever they were feeling distressed. The purpose of the coping space is to help participants recognise the difference between automatic reacting and skilful responding (Baer, 2006).

*e. Group-level inquiry of participants' experiences of the mindfulness practices*

The facilitator-led discussions of the longer in-session mindfulness practice (as well as discussions surrounding home practice) were aimed at guiding participants through three processes: i) becoming aware of thoughts, feelings and physical symptoms during the practices; ii) exploring individual reactions to noticing such stimuli (e.g., how did you

feel when your mind wandered; what did you do when your mind wandered) and, iii) integrating this knowledge into a wider context of understanding, thereby developing an idiosyncratic understanding of these experiences within everyday life, for example, to develop an understanding of how depression is triggered and perpetuates itself (Segal *et al.*, 2002). Participants were encouraged to develop an understanding of how stress, anxiety and depression are triggered and possibly maintained for them. Later in the course, participants were encouraged to develop a different way of relating to their thoughts, sensations and feelings. Specifically, participants were encouraged to develop mindfulness acknowledgement and acceptance of unwanted internal experiences, rather than habitual, automatic responses that tend to perpetuate difficulties (Segal *et al.*, 2002). In sum, the ultimate aim of these discussions was to encourage participants to develop an understanding of their own warning signs regarding emotional disturbance, in order to choose a more skilful response to dealing with these (Segal *et al.*, 2002).

*f. Explanation of the following week's home-practice and course tasks*

Sufficient time was left remaining at the end of each session for instruction regarding the home-based practice for the following week. This was important as it reiterates the importance of the home-based practice (Segal *et al.*, 2002).

## **2.6 Measures**

*Where copyright permitted, copies of the standardised measures are included in the Appendix section (Appendix 8, 9, 10 & 12).*

### **2.6.1 Demographic Questionnaire**

A brief questionnaire (Appendix 7) was designed to collate data on participants' age, gender, level of education, occupation and parenting status (e.g., co-parenting, lone parenting, and sharing parenting duties with another parent in a different household). The questionnaire also asked about the child's medical diagnosis and the age of the child when the diagnosis was made.



### 2.6.2 *The Hospital Anxiety and Depression Scale*

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was used as a brief screening instrument in the current study, though not as the main measure of anxiety and depression. The HADS was developed as a measure of anxiety and depression in general medical outpatient settings. It is a brief, self-report questionnaire that consists of 14-items; a 7-item subscale designed to measure anxiety and a 7-item subscale designed to measure depression. Respondents are requested to consider each item in relation to the extent to which they have felt this way during the past week and to specify their response on a 4-point Likert scale. Each item yields a score between 0 and 3 and a total score for each subscale is derived by summing all the item scores for that sub-scale. Zigmond and Snaith (1983) proposed a series of clinically derived cut-off scores for distinguishing psychological well-being from abnormally elevated levels of psychological distress. For both subscales, scores in the range of 0 to 7 are considered 'Normal', 8 to 10 as 'Mild', 11 to 15 as 'Moderate' and 16 to 21 as 'Severe'. In a subsequent review of 747 articles, Bjelland *et al.* (2002) reported that a score of 8 on either of the subscales represents the optimal cut-off score for caseness, for both anxiety and depression. A copy of the HADS is presented in Appendix 8.

#### *Psychometric Properties of the HADS*

Each subscale of the HADS is reported to have high internal consistency, with correlation coefficients ranging between  $r=.80$  and  $r=.93$  for the anxiety subscale and  $r=.81$  and  $r=.90$  for the depression subscale (Herrmann, 1997). The scale has also been demonstrated to have good external validity (Bjelland *et al.*, 2002). It has been found to reliably detect anxiety and depression and to perform well in assessing symptom severity (Zigmond and Snaith, 1983). The HADS is widely used as a screening instrument in both clinical and research settings. The advantages of the HADS is that it is brief and simple to administer, it seems to separate anxiety from depression and it is not confounded by physical illness to the same extent as measures that include many items tapping somatic symptoms (McDowell, 2006). It has also been deemed appropriate for use with both psychiatric and general populations (Bjelland *et al.*, 2002).



### *Limitations of HADS*

Although the HADS has been found to be a useful tool for screening for anxiety and depression (Moorey *et al.*, 1991), critics argue that it should not be used as a diagnostic tool based on its narrow definitions of depression and anxiety. Somatic aspects of depression have also been reduced in the scale, so that symptoms due to physical illness do not erroneously contribute to depression or anxiety scores, thereby making the scale more suitable for patients with co-morbid physical complaints (Dunbar *et al.*, 2000). Therefore, for the purpose of measuring anxiety and depression at the different time-points in the present study, the more comprehensive Beck Anxiety Inventory (BAI; Beck *et al.*, 1988) and Beck Depression Inventory- II (BDI II; Beck *et al.*, 1996) were used in order to increase sensitivity to change. There was also no reason to believe that the parent participants in the present study were suffering from acute or chronic illnesses.

### **2.6.3 The Beck Anxiety Inventory**

#### *Description of the Scale*

The Beck Anxiety Inventory (Beck *et al.*, 1988) was designed to measure the presence and severity of anxiety in adolescents and adults, as an aid to the diagnosis of anxiety in clinical settings. The scale was also designed to be able to distinguish anxiety from depression. The BAI consists of 21 items, each describing a common symptom of anxiety. The respondent is asked to rate, on a 4-point Likert scale, the degree to which they have been bothered by each symptom over the past week. Scores obtained for each item range between 0 and 3 and the items are summed to obtain one overall score, which can range between 0 and 63. The manual provides guidelines for interpreting scores, suggesting that those within the range of 0 to 7 reflect a 'Minimal' level of anxiety, 8 to 15 reflect 'Mild' anxiety, 16 to 25 as 'Moderate' anxiety and 26 to 63 as 'Severe' anxiety (Beck and Steer, 1993).

#### *Psychometric Properties of the BAI*

The BAI has been demonstrated to have excellent internal consistency in clinical ( $r = .92$ ; Beck and Steer, 1993) and non-clinical ( $r = .91$ ; Creamer *et al.*, 1995) samples. It has

also been shown to have good test-retest reliability, with correlation coefficients ranging between  $r=.75$  and  $r=.83$  (Beck and Steer, 1993; de Beurs *et al.*, 1997), in samples of outpatients. Results from studies of adult clinical populations have also demonstrated moderate to high correlations between the BAI and other well-known measures of anxiety. These include the anxiety subscale of the Symptom Checklist-90 (Derogatis, 1975), which correlated highly with the BAI, obtaining a coefficient of  $r=.81$  (de Beurs *et al.*, 1997); the Hamilton Anxiety Rating Scale- Revised (HARS-R; Hamilton, 1959), which obtained a coefficient of  $r=.51$  (Beck & Steer, 1993); and the anxiety subscale of the Depression and Anxiety Stress Scales (Lovibond & Lovibond, 1995), with a coefficient of  $r=.85$  (Antony *et al.*, 1998).

Studies have shown that the BAI correlates with the BDI-II within the range of  $r=.44$  to  $r=.62$  (Morin *et al.*, 1999; Wetherell and Arean, 1997), calling into question the ability of the scale to measure anxiety as a distinct construct. However, de Beurs *et al.* (1997) demonstrated that other anxiety measures (e.g., the State-Trait Anxiety Inventory; Spielberger *et al.*, 1983) have higher correlations with the BDI-II, than the BAI, which has been explained in terms of a common negative affect factor that may underlie both conditions (McDowell, 2006). This in mind, the BAI appears to have just as good, if not better, discriminative validity in comparison to other anxiety measures. In support of this, the BAI has been shown to discriminate well between outpatients diagnosed with depression and those diagnosed with anxiety disorders (Beck *et al.*, 1988; Steer *et al.*, 1993). The BAI is also a reasonably brief measure to administer.

#### **2.6.4 The Beck Depression Inventory**

##### *Description of the Scale*

The Beck Depression Inventory-II (Beck *et al.*, 1996) is a revised version of the Beck Depression Inventory (Beck *et al.*, 1961), designed to measure the presence and severity of depression. This revised version was developed in accordance with the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV; 2000), which changed many of the diagnostic criteria for Major

Depressive Disorder. The BDI-II is a 21-item, multiple choice, self-report inventory, with each item consisting of a list of four statements arranged in increasing severity about a particular symptom of depression. Respondents are asked to consider each item in terms of how they have felt over the preceding two weeks and to specify their response on a 4-point Likert scale. Item scores range from 0 to 3 and one overall score is derived by summing the individual item scores. According to the manual, scores falling within the range of 0 to 13 should be classified as 'Minimal Depression', 14 to 19 as 'Mild Depression', 20 to 28 as 'Moderate Depression' and 29 to 63 as 'Severe Depression'.

#### *Psychometric Properties of the BDI-II*

Studies examining the psychometric properties of the BDI-II have demonstrated good reliability and validity. In examining the factor structure of the BDI-II, Beck *et al.* (1996) found evidence for a two-factor solution; cognitive and somatic symptoms. Each of these factors has emerged consistently in the depression literature (Arnau *et al.*, 2001; Beck *et al.*, 1996; Dozois *et al.*, 1998). This instrument has been demonstrated to have high internal consistency, with coefficient alphas of .92 for psychiatric outpatients and those ranging between .91 and .93 for the general population (Beck *et al.*, 1996; Dozois *et al.*, 1998; Steer *et al.*, 1998). The BDI-II has also been found to have good test-retest reliability with both clinical ( $r = .93$ ) and non-clinical ( $r = .96$ ) populations (Beck *et al.*, 1996; Sprinkle *et al.*, 2002).

Beck *et al.* (1996) also found that the BDI-II correlates significantly with other well-known measures of depression, including the Hamilton Rating Scale for Depression (Hamilton, 1960) and the Beck Hopelessness Scale (Beck *et al.*, 1974). Krefetz *et al.* (2002) also found that the BDI-II and the Reynolds Adolescent Depression Scale (Reynolds, 1987) correlated highly. Research has also demonstrated that the BDI-II scores correlate more highly with measures of depression than with measures of anxiety (Beck *et al.*, 1996; Steer *et al.*, 1997). The low correlations between the BDI-II and gender, age, ethnicity and social desirability lends further support for the scale's

discriminative validity (Steer and Clark, 1997). The BDI-II has also been found to discriminate well between varying levels of depressive symptomatology, as measured by clinical interviews which were used to make psychiatric diagnoses according to the International Classification of Disease- 10<sup>th</sup> edition (ICD-10; World Health Organisation, 1992) criteria, demonstrating support for the specificity and sensitivity of the measure (Furlanetto *et al.*, 2005). It also differentiates well between depressed and non-depressed persons (Arnau *et al.*, 2001; Beck *et al.*, 1996).

The BDI-II is one of the most frequently used measures for identifying the presence and severity of depression in both the general and psychiatric populations, in both clinical and research contexts (Beck *et al.*, 1996; Dozois *et al.*, 1998; Steer *et al.*, 1998). As well as having good psychometric properties, this measure is relatively brief and user-friendly.

#### **2.6.5 The Cognitive and Affective Mindfulness Scale – Revised**

##### *Description of the Scale*

The Cognitive and Affective Mindfulness Scale- Revised (CAMS-R; Feldman *et al.*, 2004; Feldman *et al.*, 2007) is a 12-item inventory designed to measure four components thought to comprise the overall construct of mindfulness. These include: 1) the ability to regulate attention, 2) to attend to sensations, thoughts, feelings and aspects of one's environment in the present moment, 3) awareness of experience, including feelings, thoughts and sensations and 4) an attitude of acceptance and non-judgement towards such experiences. Respondents are requested to specify on a 4-point Likert scale the frequency that each statement applies to them (1 = rarely/not at all to 4 = always). Although the scale was designed to capture several elements of mindfulness, it yields one overall score ranging from 12 to 48. The total score is produced by summing all the items, with the exception of items 2, 6 and 7, which are reverse scored. Higher scores represent a greater degree of mindfulness. A copy of the CAMS-R is presented in Appendix 9.

### *Psychometric Properties of the CAMS-R*

The CAMS-R is a revised version of the Cognitive and Affective Mindfulness Scale (CAMS; Kumar *et al.*, 2005). The 18-item CAMS has been demonstrated to be sensitive to change and to have concurrent validity (Kumar *et al.*, 2005). However, the internal consistency was low (Kumar *et al.*, 2005). As the CAMS-R is a relatively new measure, its psychometric properties require further evaluation. However, the authors reported promising preliminary findings. Firstly, Feldman *et al.* (2006) demonstrated support for the 4-factor structure. These four components have been emphasised in several definitions of mindfulness (Bishop *et al.*, 2004; Kabat-Zinn, 2003). An acceptable level of internal consistency in the 12-item total score has also been demonstrated by Feldman *et al.* (2006;  $r = .74$  to  $r = .77$ ) and by Baer *et al.* (2006;  $r = .81$ ). Total scores on the CAMS-R have also correlated highly with total scores on other measures of mindfulness, such as the Friedberg Mindfulness Inventory (FMI; Buchheld *et al.*, 2001) and the Mindfulness Attention Awareness Scale (MAAS; Brown and Ryan, 2003).

Increases in mindfulness scores have been observed in a sample of individuals completing an exposure-based cognitive therapy intervention for depression, using the 18-item version of the original CAMS. The authors reported using this version of the CAMS since the CAMS-R had not been developed when their study was conducted (Kumar *et al.*, in press). However, there is limited research examining the sensitivity of the CAMS-R to change. Therefore, the principal researcher contacted the main author of the scale to determine their view on the suitability of the scale for this purpose. G. Feldman (personal communication, 31<sup>st</sup> January 2008) suggested that based on ongoing studies and unpublished research conducted by the scale's authors, the introduction to the scale could be modified to increase the sensitivity of this measure to change in mindfulness following mindfulness training. Specifically, this involved modifying the prompt to reflect mindfulness during a fixed period of time by adding 'during the past week' to the end of the questions. In addition, the CAMS-R appears to use more user-friendly language than some of the other mindfulness scales (e.g., MAAS, FMI), bringing a complex abstract concept to an understandable level. This measure, thus, has



the advantage of being relatively easy to understand for people who have little or no experience of mindfulness approaches.

#### **2.6.6 The Acceptance and Action Questionnaire- 16**

##### *Description of the Scale*

The Acceptance and Action Questionnaire-16 (AAQ-16; Hayes *et al.*, 2004), is a 16-item measure which was initially developed as a measure of ACT concepts (acceptance and values-based action). The AAQ-16 was initially developed to derive one total score associated with the concept of experiential avoidance, which is the attempt to alter the form, frequency, or situational sensitivity of negative internal events (e.g., thoughts, feelings, and physiological sensations), even when doing so leads to behavioral difficulties (Hayes *et al.*, 1996). However, Bond and Bunce (2003) conducted a confirmatory factor analysis which provided support for a two factor solution; acceptance (willingness to experience internal events, including those that are uncomfortable), which is thought to be a central facet of mindfulness, and values-based action (ability to experience unwanted internal events in the pursuit of one's values or goals). Therefore, although the latter is not a direct measure of mindfulness, it is proposed to reflect the behavioural manifestation of acceptance. In particular the action scale measures the degree to which individuals are able to fully contact the present moment, including the thoughts and feelings one might be experiencing, without defense (acceptance), and, depending upon what the situation allows, persisting in or changing behavior in the pursuit of one's goals and values (action) (Hayes *et al.*, 2006). In short, this refers to the ability of people to live a life that includes those aspects of most importance (e.g., being a loving parent; a good partner; engaging in spirituality), even during periods of more or less difficulty (e.g., anxiety, depression). Respondents report the extent to which each statement applies to them on a 7-point Likert scale ranging from 'Never True' to 'Always True'. Items 2, 3, 4, 9, 11, 12, 13, and 15 are reverse scored. An acceptance score is derived by summing the individual items pertaining to that subscale (4, 6, 8, 10, 12, 13 & 15) and an action score is derived by summing the



individual items relating to that subscale (1, 2, 3, 5, 7, 9, 11, 14 & 16). Higher scores represent greater levels of acceptance and values-based action.

#### *Psychometric Properties of the AAQ-R*

Acceptance as a concept has only relatively recently been studied. However, preliminary findings have provided support for the AAQ-16 as a measure of acceptance and values-based action. The developers (Hayes *et al.*, 2004) reported adequate internal consistency ( $r = .70$ ) and this was also replicated in a later study conducted by Mairal (2004). Adequate test-retest reliability ( $r = .71$ ) has also been demonstrated (Hayes *et al.*, 2004). Scores on the AAQ-16 have also been found to significantly correlate with measures of depression, anxiety and phobic avoidance in both clinical and non-clinical samples (Hayes *et al.*, 2004; Mairal, 2004). The AAQ has also been found to accurately distinguish between general population and clinical samples (Hayes *et al.*, 2004; Mairal, 2004).

Although a shorter 9-item version of the questionnaire has been developed, the 16-item version was selected for use in the current study based on its proposed greater sensitivity to smaller changes during therapy (Hayes *et al.*, 2004; Bond & Bunce, 2000).

#### **2.6.7 The Parenting Stress Index- Short Form**

##### *Description of the Scale*

The Parenting Stress Index - Short Form (PSI-SF; Abidin, 1995) is a 36-item index, directly derived from the full-length PSI, a 101-item index designed to assess stress in the parent-child system. It requires completion by parents, based on their experience with children between the age of one month and twelve years. The PSI-SF yields individual scale scores and a total parenting stress score (which is the addition of the three subscale scores). The three subscales are: Parental Distress (PD), which taps the degree of distress experienced by a parent in association with their parenting role (e.g., "I feel trapped by my responsibilities as a parent" and "Since having a child, I feel that I am almost never able to do things that I like to do"); Parent-Child Dysfunctional

Interaction (PCDI), which measures parent's perceptions of stressful parent-child interactions (e.g., "My child rarely does things for me that makes me feel good" and "Sometimes my child does things to bother me just to be mean"), and Difficult Child (DC), which focuses on the characteristics of the child (e.g., "My child gets upset easily over the smallest thing" and "My child makes more demands on me than most children"). The PSI-SF is predominantly scored (33/36 items) on a 5-point Likert scale, ranging from 'Strongly Agree' to 'Strongly Disagree'. For two of the items, respondents are presented with five different sub-items and asked to select one that most closely reflects their own situation. Finally, for one of the items, respondents are required to select one particular number range (1-3, 4-5, 6-7, 8-9 & 10+) that most closely reflects the number of things that their child does that bothers them. A score and percentile rank can be obtained for each sub-scale. Total scores fall between 36 and 180, with higher scores representing greater stress within the parent-child system.

#### *Psychometric Properties of the PSI-SF*

Abidin (1995) demonstrated that the total score of the PSI-SF correlates highly with the long version of the PSI (Abidin, 1983;  $r = .94$ ), which has been demonstrated to have robust psychometric properties. Abidin (1995) also demonstrated internal consistency coefficients of .91 (Total Stress), .87 (Parental Distress), .80 (Parent Child Dysfunctional Interaction) and .85 (Difficult Child). Test-retest reliability has also been studied over a 6-month interval, yielding stability coefficients of .84 (Total Stress), .85 (Parental Distress), .68 (Parental Child Dysfunctional Interaction) and .78 (Difficult Child). Reitman *et al.* (2002) demonstrated that the PSI-SF accurately discriminates between varying levels of parental distress, as measured using a self report questionnaire (Brief Symptom Inventory; Derogatis & Melisaros, 1983), and between varying levels of difficult child behaviour, as measured using a standardised behaviour rating scale completed by parents (Conners Parent Rating Scale; Conners, 1997). The PSI-SF has also been demonstrated to be clinically sensitive to change following interventions (Rush, 2007).

The PSI-SF has also been used extensively in clinical and research settings, including paediatric settings (Wen Hung *et al.*, 2004). In addition to its good psychometric properties and the existing empirical support for a 3-factor model of parenting stress, the PSI-SF is considered to be a user-friendly measure (Rush, 2007).

### **2.6.8 The Strengths and Difficulties Questionnaire**

#### *Description of the Scale*

The Strengths and Difficulties Questionnaire (parent's version) (SDQ; Goodman, 1997) is a brief behavioural screening questionnaire, to be completed by parents who have children between the ages of 3 and 16 years. The SDQ consists of 25-items, which asks about the child's behavior 'over the last six months or this school year'; 19 items tap perceived difficulties, 5 items tap perceived strengths and one item is neutral ('Gets on better with adults than with other children'). The SDQ contains 5 sub-scales (consisting of 5 items in each), which relate to emotional symptoms, conduct problems, hyperactivity and inattention, peer relationship problems and prosocial behaviour. Each perceived difficulties item is scored on a 0-2 scale (0= not true, 1= somewhat true, 2= certainly true). Each perceived strengths item is scored in the reverse manner (2= not true, 1= somewhat true, 0= certainly true). Scores can be derived for each of the subscales by summing the scores of the 5 items. A 'total difficulties' score can be derived by summing the scores of all the scales, except the prosocial scale. The developers have proposed a classification system based on extensive normative data (10,298 parents from the United Kingdom; Meltzer *et al.*, 2000). With regards to the Total Difficulties Scale, scores fall into the categories 'normal' (0-13), 'borderline' (14-16) and 'abnormal' (17-40). A table displaying the classification system for the subscales is presented in Appendix 11. The SDQ also has an optional additional 'impact supplement', which taps chronicity, distress, social impairment and burden to others. The inclusion of this extended form has been recommended when measuring outcomes, in order to increase the measures sensitivity to change (Mathai *et al.*, 2003). For the impact supplement, the authors suggest that the items are summed to generate an impact score that ranges from 0 to 10. A Copy of the SDQ is included in Appendix 12.

The authors of this scale have also developed a follow-up questionnaire (SDQ-F), which includes the same 25-items as the SDQ and the impact items. To increase the chance of detecting change, the follow-up version asks about 'the last month', as opposed to 'the last six months or this school year'. This version of the measure was administered at post-treatment and at three months follow-up.

### *Psychometric Properties of the SDQ*

Goodman (2001) recently conducted a nationwide study involving ten thousand parents of children aged between 5-15 years, to examine the psychometric properties of the scale. Factor analyses predicted the 5 factor structure. The internal consistencies across the sub-scales were generally satisfactory (ranging from  $r=.57$  to  $r=.82$ ), particularly for the total difficulties score ( $r=.82$ ). Muris *et al.* (2003). Test-retest coefficients over a two month interval for the various subscales ( $r=.75$  to  $r=.91$ ) and the total score ( $r=.88$ ) were also satisfactory.

The SDQ has also demonstrated high correlations with the Rutter Questionnaire (Elander & Rutter, 1996) and with the Child Behaviour Checklist (CBCL; Achenbach, 1991), which have well-established validity and reliability (Goodman, 2001). The SDQ, CBCL and Rutter questionnaires were also found to be able to discriminate equally well between child mental health attendees and community controls (Goodman, 1997, 2001). The SDQ has also been found to perform as well as the much longer CBCL, in terms of assessing internalising and externalising problems. In addition to this, unlike the CBCL, very little overlap has been found between the items loading on the internalising scale (Emotional Symptoms) and the externalising scale (Conduct Problems & Hyperactivity/Inattention) of the SDQ, demonstrating that the scales are relatively uncontaminated by one another (Goodman, 2001; Goodman & Scott, 1999). The SDQ has also gained support for use with parents of chronically ill children, given its increased sensitivity and specificity in detecting emotional and behavioural problems within this population, in comparison to other well-known measures (e.g. CBCL), which have tended to include a large number of items relating to physical symptoms and are validated in general

population samples (Hysing *et al.*, 2007; Perrin *et al.*, 1991). The clinical sensitivity of the SDQ has been relatively understudied. However, one study conducted by Mathai *et al.* (2003) demonstrated support for the sensitivity of the SDQ as a clinical outcome measure at six-months post-intervention, as measured against clinician's ratings on the Health of the Nation Outcome Scales for Children and Adolescents (HoNOSCA; Gowers *et al.*, 1998). The authors have recommended the use of the SDQ as a measure for evaluating the outcomes of interventions.

The SDQ has become increasingly popular in recent years, being translated into several different languages and has been used in the National Health Interview Survey (NHIS; National Centre for Health Statistics, 2003). The reliability and validity of the SDQ make it a useful brief measure of the behaviour and psychological-wellbeing of children and adolescents (Goodman, 2001). The inclusion of 'strengths' also aims to increase the acceptability of the SDQ to parents (Goodman, 1999). Research has also found that parents tend to favor the SDQ over the CBCL (Goodman and Scot, 1999). The developers have also provided permission for the use of this measure, making it a relatively inexpensive option.

#### **2.6.9 The Course Evaluation Form**

An evaluation form (Appendix 13) was designed to investigate participants' opinions of the course. It was considered necessary to gather information that would enable any future courses to be tailored in ways that would make them more accessible and useful to participants. The evaluation form measured participants' views regarding various practical aspects of the course (e.g., the time and location of the meetings, the duration of the course and the home-based practice), as well as various aspects regarding course delivery and content (e.g., the manner of the course facilitators, the relevance of the material presented and discussed, and the usefulness of the course). This was measured using a closed-response format, using two types of scales (strongly agree, agree, disagree, strongly disagree and yes, no, don't know), depending on the question.



Various open-response items were also included in the measure, tapping: (1) whether participants would have liked to be informed about anything additional before agreeing to take part in the course, (2) what was helpful about the course, (3) what was challenging about the course, (4) what advice they would give to someone that was interested in taking part in the course. There was also space for participants to make any additional comments.

## **2.7 Ethical Issues**

### **2.7.1 *Potential Distress to Participants***

It was postulated that some individuals might express an interest in the study who did not meet the criteria for inclusion. It was decided that in such cases, discussion would take place with the individual about alternative sources of support.

It was also appreciated that MBSR, like other well-known therapies (e.g., Cognitive Behavioural Therapy, Schema Focused Therapy) can bring to the fore-front, painful emotions, which might have been suppressed for many years (Segal *et al.*, 2002). The course facilitators continually monitored the wellbeing of participants as the course progressed, to ensure that support and advice were offered if needed. It was postulated that, in the face of extreme distress, participants would be advised of additional sources of help (e.g., Adult Mental Health services). It was agreed that if such circumstances arose, the primary researcher and her field supervisor would discuss the issue with the participant and seek consent to write to their general practitioner detailing the nature of these discussions and indicating their professional opinion of the best way forward. Despite this, there were no instances in which such procedures were required.

### **2.7.2 *Informed Consent***

During the pre-group meeting, it was highlighted to participants that they were free to decline to participate and that this would in no way affect their own or their child's care. Careful consideration was also given to ensuring that participants were provided with sufficient information to make fully-informed decisions of whether or not to participate.



### **2.7.3 Confidentiality**

The confidential nature of all information collected as part of the study was emphasised to participants on the information sheet (Appendix 3) and during the pre-group meeting. A series of measures was employed to ensure the highest standards of confidentiality. Each participant was assigned a number for identification. All questionnaire data was then completely anonymised, transferred to and stored on a password protected NHS computer. Returned questionnaires were stored safely in a locked filing cabinet. Individual identification numbers assigned to each participant's anonymised data were the only link to their personal information. Personal information, such as name and address, was stored in a locked filing cabinet in the principal researcher's consulting room, on NHS premises. Only the researcher and her field supervisor had access to this data. Data from the study will be stored securely in a locked cabinet on NHS premises for five years, in accordance with research governance guidelines, and subsequently destroyed.

### **2.7.4 Ethical Approval**

Ethical approval was obtained from the North of Scotland Research Ethics Committee on the 3rd October 2007. A copy of the correspondence granting approval is included in Appendix 14. Subsequently, the study was registered with NHS Grampians' Research and Development office and on the 11<sup>th</sup> October 2007 approval was given for the study to proceed (Appendix 15).

## **2.8 Sample size**

Sample size estimation depends on the strength of the effect that we are trying to detect (effect size) and the amount of statistical power that we want in order to be able to detect such effects (Field, 2005). Clark-Carter (2004) proposed a method of calculating the required sample size for non-parametric Wilcoxon Matched Pairs Signed-Rank Tests. This involved calculating the required sample size for a within-subjects t-test, based on the appropriate effect size and power, and then multiplying the sample size by 1.05.

An estimated effect size for the current study was calculated based on effect sizes obtained by well-designed studies involving MBSR and MBCT, with similar populations. Effect sizes from MBCT studies were included in the estimation considering the current study comprised the central elements of this approach. This was the first published study to have included the CAMS-R as an outcome measure and, since neither the PSI-SF nor the SDQ have been included in similar studies, the effect sizes included in the estimation were based on the BAI and the BDI, which pertain to the second principal hypothesis.

The effect sizes obtained across studies ranged between 0.77 and 1.5 (Finucane & Mercer, 2006; Kabat-Zinn *et al.*, 1992; Kenny & Williams, 2007). Therefore, based on an effect-size of 0.8, and a high level of statistical power (0.8), assuming an alpha value of 5 percent, the minimum sample size required for the current study was 12.

## **2.9 Analysis**

Data was analysed using a statistical software package developed for the social sciences SPSS for windows (version 15.0). Prior to formal statistical analysis of the data, some exploratory data analysis was conducted, including consideration of the distribution of data. Visual inspection of data plots suggested that the data did not appear to meet the assumptions of parametric statistics. Nonparametric tests make fewer assumptions about the nature of the data population and can be appropriate for small data sets where assumptions of normality may not be met and where tests of normality lack power. In view of this, the Wilcoxon Matched Pairs Signed-Rank test was used to assess for significant changes across the three time points (baseline; post-treatment, and follow-up).

Cohen's  $d$  was used to calculate effect sizes where both significant and non-significant differences were found. This involved dividing the difference between the means by the standard deviation at baseline (Cohen, 1992). The author recognises the limitations of

presenting parametric effect sizes when the data are potentially unsuited to this, though deemed it preferable to include effect size calculations. This method also enables comparisons to be made with similar studies including between subjects designs (Clark-Carter, 2004). These issues will be considered further in the discussion section of this manuscript (5.3.5).

**Chapter 3: Results (Part A): Characteristics of Sample & Principle Data Analysis**

This section will describe the characteristics of the sample and present the findings from the principle data analysis, pertaining to the primary and secondary hypotheses.

**3.1 Participants**

A total of nine participants took part in this study, eight of whom completed the intervention course. Twelve parents expressed an interest in the study. However three of these parents did not meet the inclusion criteria. Two had children who did not have a medical condition and one had a baby (three months old) who was below the age range for inclusion in the study. All of the remaining nine parents were assessed during the pre-group meeting, met the inclusion criteria and were invited to participate in the study. One of the nine participants dropped out of the study after the first group meeting.

**3.1.1 Background Characteristics of Sample**

Of the eight participants who completed the intervention, seven were British and spoke English as their first language. The other participant spoke fluent English as a second language. The sample consisted of 2 males and 6 females. Table 3.1 displays the means, standard deviations and range for the demographic variables of (i) age of participants, (ii) age of child, (iii) years since the child’s diagnosis.

**Table 3.1:** Means and standard deviations of the ages of participants and their children, and the length of time since the child’s diagnosis (years)

<u>Demographic Characteristic</u>	<i>M</i>	<i>SD</i>	Min.	Max.
Age of Participating Parents	40.13	6.62	28	47
Age of Chronically Ill Child	7.75	3.69	3	12
Years since child diagnosed	3.57	3.76	0.25	12

Only one parent per chronically ill child was recruited. Four participants had a male child and four participants had a female child, all of whom were suffering from a chronic medical condition. These conditions included type 1 diabetes, cancer, brain tumour, chronic renal failure, ocular motor apraxia, cystic fibrosis and chronic reflux and choking. Of these, diabetes was the most common diagnosis (2 participants).

With regard to educational attainment, one participant specified school as their highest level of education, four participants specified college and three participants reported having attended university. Four participants worked as a homemaker, two participants were in full-time employment and two participants were in part-time employment. With respect to parenting status, seven participants were co-parenting and living in the same household as the other parent and one participant reported sharing parenting duties with another parent, living at a different address. Each participant's social class was coded on the basis of their current occupation (or last occupation where a participant was working as a homemaker or not employed) according to the Office of Population Censuses and Surveys (1980) Classification of Occupations. Table 3.2 displays the distribution of occupational codes in the present sample.

**Table 3.2:**      Distribution of Occupational Codes (SES) for Participants

	Social Economic Status (SES)				
	1	2	3	4	5
Number of Participants	1	3	2	1	1
Sample Percentage (%)	12.5	37.5	25	12.5	12.5

**3.2      Exploratory Analysis**

In order to investigate whether the results obtained in the current study were normally distributed, data plots were visually inspected. As the data did not appear to meet assumptions for parametric statistics, non-parametric statistics were employed.

### 3.3 Principle Data Analysis

Wilcoxon Matched Pairs Signed-Rank tests were used to investigate the effectiveness of the MBSR course. Therefore, participants' pre-treatment scores on the CAMS-R, AAQ, BAI, BDI, PSI-SF and SDQ were compared with those at post-treatment and at three months follow-up.

Post-treatment effect sizes (using Cohen's  $d$ ) were calculated by dividing the pre- to post-treatment difference by the pre-treatment standard deviation, whereas those at follow-up were calculated by dividing the pre- to follow-up difference by the pre-treatment standard deviation (Cohen, 1992). The resultant effect size was interpreted based on Cohen's (1992) guidelines, where 0.2 is indicative of a small effect size, 0.5 a medium and 0.8 a large effect size.

### 3.4 Primary Hypotheses

**3.4.1 Hypothesis 1:** *Participants who take part in the MBSR course will report higher levels of mindfulness post-treatment and at 3-months follow-up than at pre-treatment.*

Medians and Interquartile Ranges (IQR) for pre, post and follow-up scores for the CAMS-R and the AAQ are presented in Table 3.3. The results from the Wilcoxon Matched-Pairs Signed-Ranks tests ( $z$  and two-tailed  $p$  values) are displayed in Table 3.4, which demonstrates significant increases in mindfulness and acceptance post-treatment (CAMS-R,  $z=-2.12$ ;  $p=0.034$  & AAQ: Acceptance,  $z=-2.12$ ;  $p=0.034$ ) and at three months follow-up (CAMS-R,  $z=-2.04$ ;  $p=0.042$  & AAQ: Acceptance,  $z=-2.37$ ;  $p=0.018$ ), compared to pre-treatment.

Effect sizes for the CAMS-R and the Acceptance scale of the AAQ were, respectively,  $d=1.28$  and  $d=0.59$  at post-treatment and  $d=1.28$  and  $d=0.91$  at follow-up. There were no significant differences on the Action scale of the AAQ at post-treatment or at follow-up, although the effect sizes were  $d=0.49$  and  $d=0.56$ , respectively.



**Table 3.3:** Median and Interquartile Ranges for Pre-Treatment, Post-Treatment and 3-Month Follow-up scores on the CAMS-R and the Acceptance and Action scales of the AAQ

Measure	Pre-Treatment		Post-Treatment		Follow-up	
	Median	IQR	Median	IQR	Median	IQR
CAMS-R	27	6.5	33.5	4.5	33	7.5
AAQ: Acceptance Scale	27	8.0	28.5	10.5	31	6.5
AAQ- Action Scale	33	9.5	35	10.0	35.5	10.5

CAMS-R = Cognitive and Affective Mindfulness Scale- Revised; AAQ = Acceptance and Action Questionnaire

**Table 3.4:** Wilcoxon Matched-Pairs Signed-Rank tests comparing pre-treatment scores on the CAMS-R and the Acceptance and Action scales of the AAQ to those at post-treatment and 3-month follow-up

Measure	Post-Treatment (N=8)		Follow-up (N=8)	
	<i>z</i>	<i>p</i>	<i>z</i>	<i>p</i>
CAMS-R	-2.12	0.034*	-2.04	0.042*
AAQ- Acceptance Scale	-2.12	0.034*	-2.37	0.018*
AAQ- Action Scale	-0.84	0.401	-1.41	0.159

\*  $p < 0.05$ ; CAMS-R = Cognitive and Affective Mindfulness Scale- Revised; AAQ = Acceptance and Action Questionnaire

**3.4.2 Hypothesis 2:** *Participants taking part in the MBSR course will report lower levels of anxiety and depression post-treatment and at 3-months follow-up than at pre-treatment.*

Medians and Interquartile Ranges (IQR) for pre, post and follow-up scores for the BAI and BDI are presented in Table 3.5. Wilcoxon Matched-Pairs Signed-Rank tests indicated significant reductions in anxiety and depression at post-treatment (BAI,  $z=-2.18$ ;  $p=0.030$  & BDI,  $z=-2.37$ ;  $p=0.018$ ) and follow-up (BAI,  $z=-2.38$ ;  $p=0.017$  & BDI,  $z=-2.52$ ;  $p=0.012$ ), relative to pre-treatment (Table 3.6). Effect sizes for the BAI and the BDI were, respectively,  $d=0.54$  and  $d=1.01$  at post-treatment and these increased to  $d=0.64$  and  $d=1.21$  at follow-up.

**Table 3.5:** Median and Interquartile Ranges for Pre-Treatment Post-Treatment and 3-Month Follow-up scores on the BAI & BDI

Measure	Pre-Treatment		Post-Treatment		Follow-up	
	Median	IQR	Median	IQR	Median	IQR
BAI	14	21	11.5	14.0	9.0	11.0
BDI	28	13	12.5	11.5	15.5	12.5

BAI = Beck Anxiety Inventory; BDI = Beck Depression Inventory

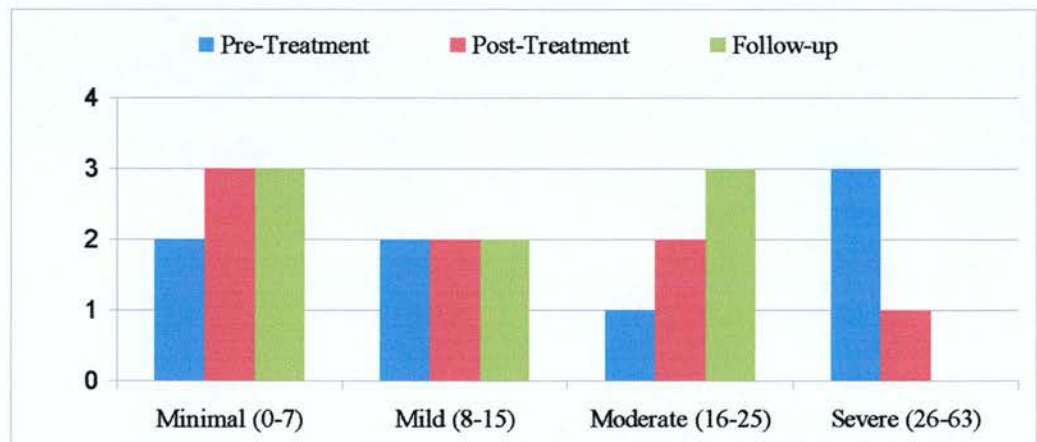
**Table 3.6:** Wilcoxon Matched-Pairs Signed-Rank tests comparing pre-treatment BAI & BDI to those at post-treatment and 3-months follow-up

Measure	Post-Treatment (N=8)		Follow-up (N=8)	
	$z$	$p$	$z$	$p$
BAI	-2.18	0.030*	-2.38	0.017*
BDI	-2.37	0.018*	-2.52	0.012*

\*  $p<0.05$ ; BAI = Beck Anxiety Inventory; BDI = Beck Depression Inventory

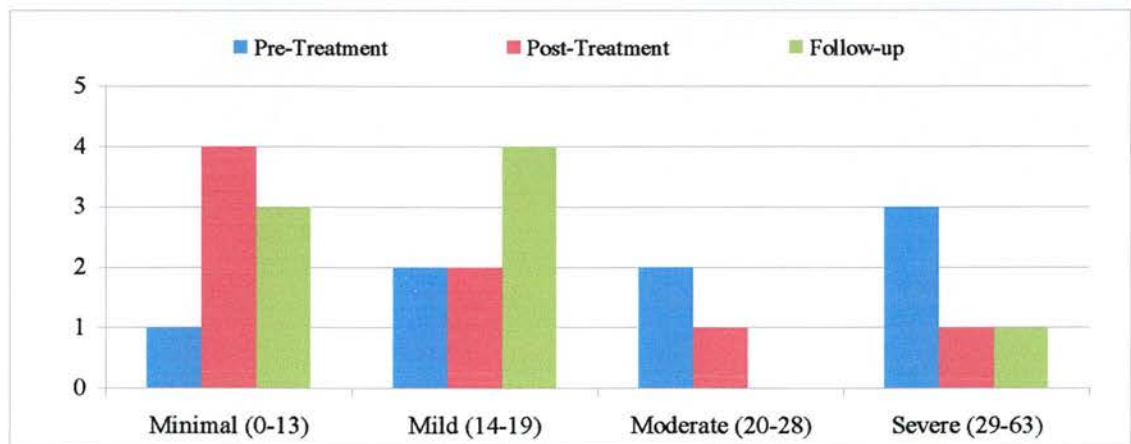
The proportion of participants who scored within each range (minimal, mild, moderate & severe) on the BAI and BDI, at the pre-, post- and follow-up treatment, are presented in Figure 3.1 and Figure 3.2, respectively.

**Figure 3.1:** Pre, Post and Follow-up Treatment Severity Range on the Beck Anxiety Inventory



As indicated by Figure 3.1, four of the eight participants had moderate or severe depression at pre-treatment and this reduced to three at post-treatment and follow-up, with no participants scoring within the severe range at the latter time-point.

**Figure 3.2:** Pre, Post and Follow-up Treatment Severity Range on the Beck Depression Inventory



As can be seen from Figure 3.2, whereas five of the eight participants had moderate or severe depression at pre-treatment, only two were in this range post-treatment and this reduced to one by the time of the three month follow-up.

### **3.5 Secondary Hypotheses**

**3.5.1** *Hypothesis 3: Participants taking part in the MBSR course will report less difficulty associated with parenting post-treatment and at 3-months follow-up than at pre-treatment.*

The Medians and Interquartile Ranges (IQR) for pre, post and follow-up scores for the PSI-SF total score and subscale scores, including Parental Distress (PD), Parent-Child Dysfunctional Interaction (PCDI) and Difficult Child (DC) are presented in Table 3.7.

Wilcoxon Matched-Pairs Signed-Ranks tests (Table 3.8) revealed a significant difference between pre- and post- treatment time points for the PD subscale ( $z=-2.24$ ;  $p=0.025$ ) of the PSI-SF, whilst the difference between pre and post treatment scores on the PCDI subscale was slightly below the level of significance ( $z=-1.86$ ;  $p=0.063$ ). The former demonstrates improvements in parental distress associated with parenting and the latter indicates an increase in perceived difficulties associated with parent-child interaction. Significant improvements were also obtained on the PD subscale ( $z=-2.52$ ;  $p=0.012$ ) at follow-up, relative to pre-treatment.

The calculated pre-post effect sizes were  $d=0.47$  and  $d=0.43$  for the PD and PCDI subscales respectively. The effect sizes at follow-up for the PD subscale and the PCDI were  $d=0.95$  and  $d=0.04$ , respectively. Those pertaining to the DC subscale at post-treatment and follow-up were  $d=0.28$ ; representing an increase relative to pre-treatment, and  $d=0.04$ ; representing a slight decrease.

**Table 3.7:** Median and Interquartile Ranges for Pre-Treatment, Post-Treatment and 3-Month Follow-up Scores on the PSI-SF

Measure	Pre-Treatment		Post-Treatment		Follow-up	
	Median	IQR	Median	IQR	Median	IQR
PD Subscale	39.5	15.5	33.5	19.5	26	6.25
PCDI Subscale	30.0	10.5	36.5	13.5	30.5	17
DC Subscale	35.0	25.0	38.0	28.0	34	30.5
<b><i>PSI-SF Total Score</i></b>	<b><i>105</i></b>	<b><i>42</i></b>	<b><i>110</i></b>	<b><i>57.5</i></b>	<b><i>98.5</i></b>	<b><i>58.9</i></b>

PSI-SF = Parental Stress Index- Short Form; PD = Parental Distress; PCDI = Parent-child Dysfunctional Interaction; DC = Difficult Child

**Table 3.8:** Wilcoxon Matched-Pairs Signed-Rank tests comparing pre-treatment PSI-SF scores to those at post-treatment and 3-months follow-up

Measure	Post-Treatment (N=8)		Follow-up (N=8)	
	<i>z</i>	<i>p</i>	<i>z</i>	<i>p</i>
PD Subscale	-2.24	0.025*	-2.52	0.012*
PCDI Subscale	-1.86	0.063	-0.339	0.735
DC Subscale	-0.70	0.482	-0.339	0.735
<b><i>PSI-SF Total Score</i></b>	<b><i>-0.17</i></b>	<b><i>0.865</i></b>	<b><i>-0.91</i></b>	<b><i>0.362</i></b>

\*  $p < 0.05$ ; PSI-SF = Parental Stress Index- Short Form; PD = Parental Distress; PCDI = Parent-child Dysfunctional Interaction; DC = Difficult Child

**3.5.2 Hypothesis 4:** *Participants who take part in the MBSR course will perceive improvements in their child's wellbeing post-treatment and at 3-months follow-up, relative to pre-treatment.*

Medians and Interquartile Ranges (IQR) for pre-treatment, post-treatment and follow-up scores for the SDQ scales are presented in Table 3.9. Wilcoxon Matched-Pairs Signed-Rank tests revealed no significant differences at post-treatment or follow-up, relative to pre-treatment (Table 3.10). The calculated effect sizes, at post-treatment and follow-up, relative to pre-treatment, for the SDQ Total and the subscales are, respectively: Total score ( $d=0.04$ ;  $d=0.30$ ); Emotional Symptoms ( $d=0.15$ ;  $d=0.30$ ); Conduct Problems ( $d=0$ ;  $d=0.42$ ); Hyperactivity/ Inattention ( $d=0.11$ ;  $d=0.50$ ); Peer Problems ( $d= 0.16$ ;  $d= 0.26$ ); Prosocial ( $d=0.11$ ;  $d= 0.32$ ) and Impact score ( $d= 0.12$ ;  $d= 0.20$ ).

**Table 3.9:** Median and Interquartile Ranges for pre, post and 3-month follow-up scores on the Total Difficulties Score, SDQ subscales, and Impact Score

Subscale	Pre-Treatment		Post-Treatment		Follow-up	
	Median	IQR	Median	IQR	Median	IQR
Emotional Symptoms	4	4	3.5	2	3.5	5.5
Conduct Problems	3	0.5	3	2	2	2.5
Hyperactivity/Inattention	5	4	6	6	3.5	4.5
Peer Problems	2	3	2	3	1.5	4
Prosocial	5.5	4	5	2	7	4
<b>Total Difficulties Score</b>	<b>14</b>	<b>10.5</b>	<b>17.5</b>	<b>13</b>	<b>13</b>	<b>14</b>
Impact Score	2.5	4	2	4.5	0.5	4



**Table 3.10:** Wilcoxon Matched-Pairs tests comparing pre-treatment SDQ scores (including the subscale, total and impact scores) to those at post-treatment and 3-months follow-up

Subscale	Post-Treatment (N=8)		Follow Up (N=8)	
	<i>z</i>	<i>p</i>	<i>z</i>	<i>p</i>
Emotional Symptoms	-0.74	0.457	-0.85	0.395
Conduct Problems	0.00	1.000	-1.30	0.194
Hyperactivity/Inattention	-0.38	0.705	-1.55	0.121
Peer Problems	-1.34	0.180	-0.38	0.705
Prosocial	-1.00	0.317	-0.95	0.340
<b><i>Total Difficulties Score</i></b>	<b><i>-0.17</i></b>	<b><i>0.865</i></b>	<b><i>-0.98</i></b>	<b><i>0.326</i></b>
Impact Score	-0.54	0.593	-1.29	0.197

## **Chapter 4: Results (Part B): Additional Exploratory Findings**

### **Participants Responses to the MBSR Practice Diary, Course Evaluation Questionnaire & Post-Course Mindfulness Practice Questionnaire**

This section will present exploratory findings based on participants' responses to the MBSR Practice Diary, the Course Evaluation Questionnaire and the Post-Course Mindfulness Practice Questionnaire.

#### **4.1 MBSR Course Evaluation Questionnaire**

The MBSR course evaluation questionnaire comprised both closed-response items and open-response items. Closed item responses related to practical aspects regarding the timing and location of the course and participants' views on potential modifications to the course are outlined in section 4.2.1. Further closed item responses related to the course delivery, content and usefulness of the course are outlined in section 4.2.2.

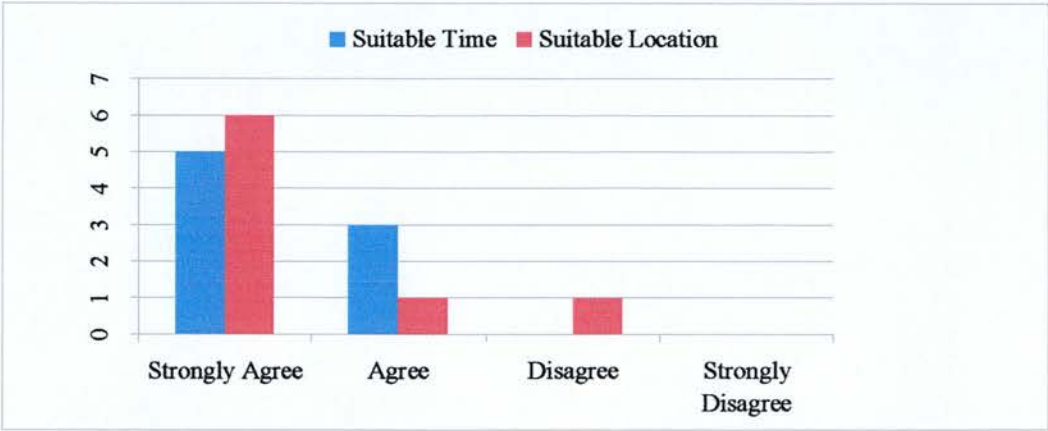
Open item responses relating to participants views on whether there were any aspects of the course they would have liked to have been informed more about before taking part in the course are presented in section 4.2.3 and the remaining open item responses were either grouped into themes (3 or more responses) or reported individually.

Participants' responses relating to the helpful and challenging aspects of the course are presented in section 4.2.4 and section 4.2.5, respectively. Participants' responses relating to advice they would give to someone interested in the course are presented in section 4.2.6.

4.1.1 Practical Aspects

Participants’ responses regarding the suitability of the time and location of the weekly group meetings are displayed in Figure 4.1.

**Figure 4.1:** Participants’ views regarding the suitability of the time and location of the MBSR course



Based on the results presented in Figure 4.1, it can be seen that all participants agreed that the course was delivered at a suitable time and seven of the eight participants agreed that the course was delivered in a suitable location.

**Figure 4.2:** Participants’ views on potential modifications to the MBSR course

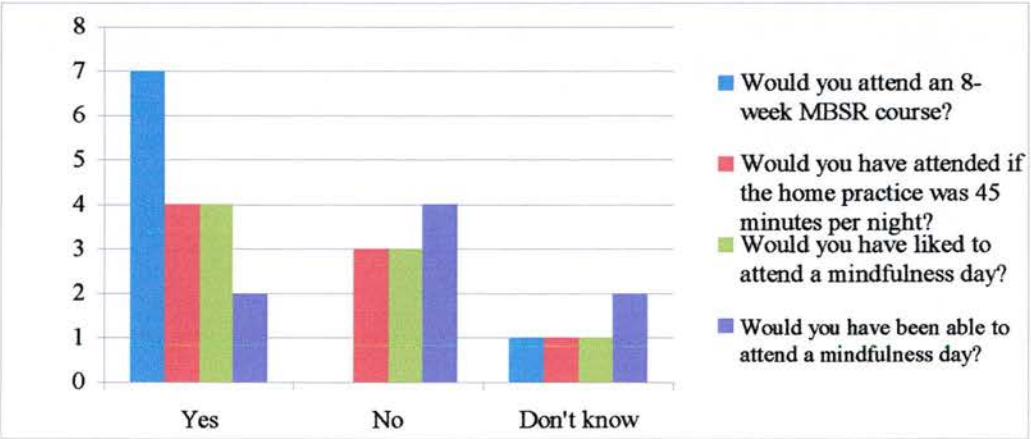
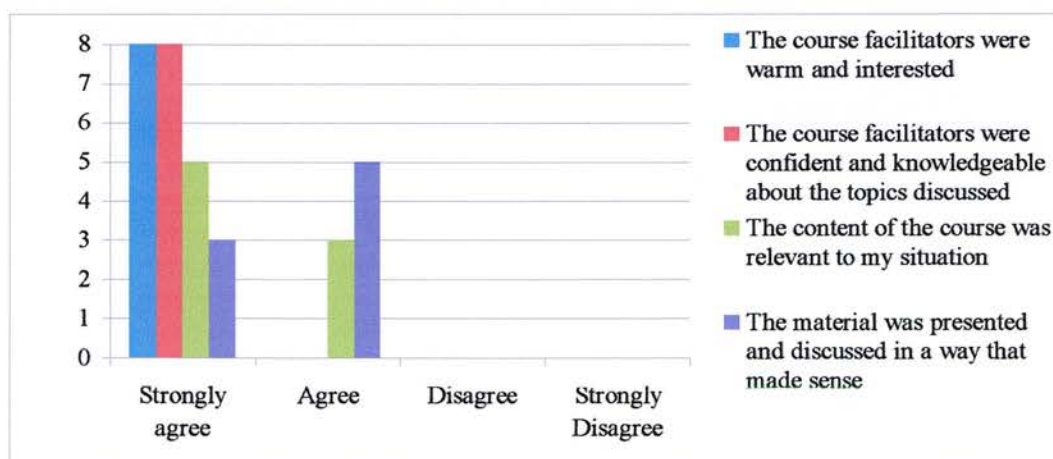


Figure 4.2 represents participants' views on potential modifications to the current course, including possible extensions to the duration of the course (from six to eight weeks) and home-based practice (from 30 to 45 minutes), as well as the inclusion of a mindfulness day (which was described within the course evaluation questionnaire). The results indicate that seven of the eight participants reported that they would have attended the MBSR course if it was 8-weeks long. However, only half of the sample (4 participants) reported that they would have attended the course if the home-based practice was the longer duration. Half of the sample (four participants) reported that they would have liked to attend a mindfulness day within the current course, although only two participants reported that they would have been able to attend.

#### 4.1.2 Course Delivery, Content & Usefulness

Participants were asked about their level of agreement with statements relating to the course facilitators, the content of the course and the way in which material was presented. Responses to these items are presented in Figure 4.3. Participants were also asked about their level of agreement with statements relating to the usefulness of the skills/knowledge gained from the MBSR course and responses to these items are presented in Figure 4.3.

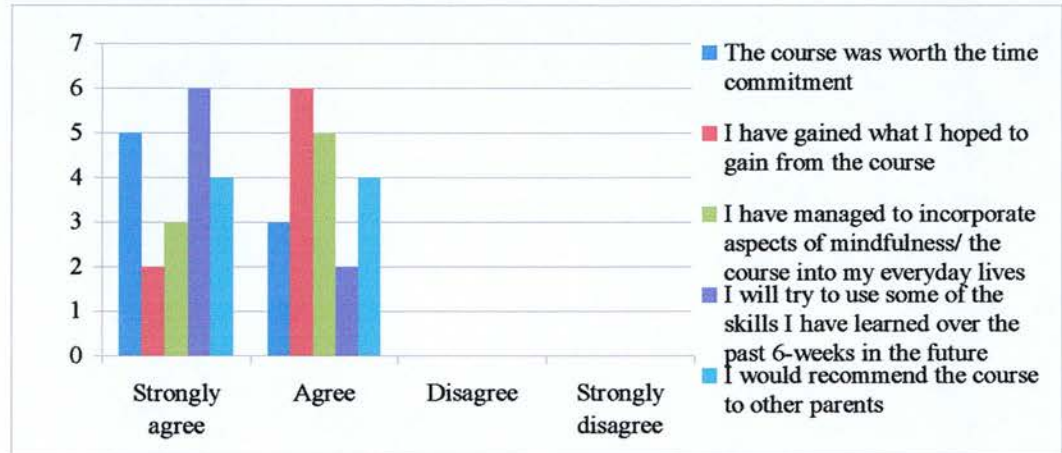
**Figure 4.3:** Participants' views regarding the manner of course facilitators, the content of the course and the clarity of the material presented





As indicated in Figure 4.3, all eight participants reported that they either agreed or strongly agreed that the course facilitators were warm and interested and confident and knowledgeable about the topics discussed and that the content of the course was relevant to their situation and made sense to them.

**Figure 4.4:** Participants' level of agreement with statements relating to the usefulness of the MBSR course



As indicated by Figure 4.4, all eight participants reported that they 'agree' or 'strongly agree' with each item relating to the usefulness of the course.

#### **4.1.3 Information Provided Prior to Participation in the Course**

All eight participants reported that there were no aspects of the course that they would have liked to obtain more information about prior to agreeing to participate.

#### **4.1.4 Helpful Aspects of the MBSR Course**

Using an open-response style, participants were asked to report any aspects of the course that they found helpful. Themes identified from participants responses are described below and individual responses are presented in Text Box 4.1.

Six participants reported that they found the realisation that other people have similar thoughts/ feelings as they do to be a helpful aspect of the course. Examples of responses within this theme are: 'Finding out that other people have thoughts the same as mine' (participant 2) and 'Meeting other parents who understood and related to how I was feeling' (participant 6). Four participants reported that they found taking the time out each day to do the practices as helpful. Examples of these participants' responses are: 'Found the time out helpful in itself' (participant 3) and 'Having time out from home' (participant 4). Further individual responses which did not fall into these or other themes are presented in Text Box 4.1.

**Text Box 4.1:** Un-themed responses relating to helpful aspects of the course

- *'To have been handed tools to help me relax'* (participant 1)
- *'It took me into the present time'* (participant 2)
- *'The presentation was great- not too formal but formal enough to all respect each others opinions'* (participant 3)
- *'Having (course facilitators) explain about depression/ anxiety/ stress'* (participant 4)
- *'It helped me to stop going over and over negative thoughts'* (participant 5)
- *'Doing different types of practice then being able to find one that suited me' & 'Being able to talk freely without feeling guilty'* (participant 6)
- *'All the aspects of the course was of some help'* (participant 7)



#### 4.1.5 Challenging Aspects of the MBSR Course

Participants were also asked to indicate any aspects of the course that they found challenging. Themes identified from participants responses are described below and individual responses which did not fall into these themes are presented in Text Box 4.2.

Three participants reported that they found aspects of the mindfulness practices themselves challenging, with responses such as ‘At times, to keep awake during some of the exercises’ (participant 5) and ‘The practices, especially breathing’ (participant 6). Three participants also reported finding the increased awareness of unpleasant thoughts/ feelings challenging, with responses such as ‘Sometimes dealing with recurring thoughts that I hadn’t noticed before how frequently I was thinking about them’ (participant 2) and ‘Focusing on myself and bad thoughts’ (participant 4).

**Text Box 4.2:** Participants’ responses relating to challenging aspects of the course

- *‘Seeing all the things written on the board and how they related to me’* (participant 2)
- *‘Speaking my thoughts during the meetings’* (participant 6)
- *‘At first, finding time for the home practice’* (participant 3)
- *‘Not pushing Feelings and thoughts away’* (participant 8)

#### 4.1.6 Participants comments related to advice they would give to someone who was interested in taking part in the MBSR Course

Participants' were asked to detail the advice they would give to someone who was interested in the MBSR course. The full range of responses obtained is presented in Text Box 4.3.

**Text Box 4.3:** Participants Responses Relating to Advice they would give to Someone Interested in the Course

- 'Do it' (participant 1 & participant 7)
- 'Go for it' (participant 2)
- 'Go for it- nothing to lose. I certainly feel that I have gained some more control in my life and my friends and family agree I am more positive...there's no point in dwelling if there's things that can't be altered. An excellent experience and a new habit I'll carry with me' (participant 3)
- 'You need to be committed to the course- i.e. attend every week and do the homework. I'm grateful I did' (participant 4)
- 'I would advise people to stick with it at the times it is challenging as it is worth the benefits' (participant 5)
- 'It is worthwhile and even if you feel it is making things worse half way through- to keep going and complete the course... an interesting 6 weeks' (participant 6)
- 'It's worth doing, helpful' (participant 8)

## **Chapter 5: Discussion**

### **Overview**

The findings of this study will be discussed in relation to the hypotheses. Possible interpretations for the findings will be explored and potential clinical implications will be considered. This section will also cover the strengths and limitations of the design, as well as possible directions for future research.

### **5.1 Interpretation of Findings**

Each hypothesis will be considered in turn.

#### **5.1.1 *Principle Hypothesis 1: Participants who take part in the MBSR course will report higher levels of mindfulness post-treatment and at 3-months follow-up than at pre-treatment.***

Participants reported significant increases in general mindfulness (CAMS-R) and in the specific facet of acceptance (Acceptance sub-scale of the AAQ) both immediately post-treatment and at three months follow-up, relative to pre-treatment (Table 3.4). These findings were, perhaps, unsurprising since the intervention was largely focused on enhancing mindfulness and much practice in the development of mindfulness skills took place over the duration of the course.

#### ***Comparison of Current Findings with Other Mindfulness-Based Interventions***

Surprisingly, few studies investigating the effectiveness of mindfulness-based interventions have included a measure of mindfulness. Rather, researchers have tended to focus their measurements on possible outcomes of increased mindfulness such as changes in anxiety, depression and pain. One possible reason for this is that, until relatively recently, there has been a scarcity of psychometrically sound tools designed to

measure the relatively complex and multi-faceted construct of mindfulness (Baer *et al.*, 2006). Indeed, given that the CAMS-R was developed relatively recently, there has been no published research using this instrument to measure change following mindfulness-based interventions. However, considering its apparent sensitivity to change within the current study, this measure appears to be an appropriate and useful tool for measuring outcomes following mindfulness-based interventions in future research.

The author acknowledges that less confidence can be placed in effect sizes obtained by studies involving small sample sizes and that direct comparison between studies is somewhat limited when different measures are used. However, when compared with those studies that have measured mindfulness before and immediately after a mindfulness-based intervention, the current findings (CAMS-R,  $d=1.28$  & Acceptance sub-scale of the AAQ,  $d=0.59$ ) appear to compare well. Indeed, the current study found a somewhat larger effect size than that obtained by Kumar *et al.* (in press) who used the 18-item CAMS to investigate the effectiveness of an exposure based cognitive therapy intervention ( $d=0.73$ ), which included a component of mindfulness. These findings are consistent with the greater focus on the development of mindfulness skills during the course involved within the current study, in view of the relatively small focus on mindfulness within the study by Kumar *et al.* (in press). Carmody and Baer (2008) also delivered an eight-week MBSR course to a sample of 174 medical patients with a variety of problems, including stress, anxiety and pain. Participants were assessed using the Five Facet Mindfulness Questionnaire (FFMQ; Baer *et al.*, 2006) and results demonstrated significant increases in mindfulness at post-treatment, compared with pre-treatment, with effect sizes for the different subscales ranging between  $d=0.47$  and  $d=0.91$ . A study conducted by Eisendrath *et al.*, (2008), investigating the effectiveness of an MBCT intervention with 51 patients suffering from treatment-resistant depression, also found a pre-post effect size for mindfulness of  $d=0.54$ , as measured by the Freiburg Mindfulness Inventory (FMI; Buchheld *et al.*, 2001). Ree and Craigie (2007) also demonstrated significant improvements in mindfulness in a sample of adult outpatients

with anxiety and depression following an MBCT intervention, as measured by the MAAS. The authors reported an effect size of  $d=0.32$ , although suggested that this was an underestimation of change due to limited sensitivity of the MAAS.

To the authors' knowledge, there is no published follow-up data on the extent of participants' mindfulness in the medium or long-term following mindfulness-based interventions. Therefore, it is unclear whether improvements in mindfulness are maintained over longer periods and how the current findings relate to larger studies in the field. Consistent with the notion that practice leads to increased mindfulness, Carmody and Baer (2008) demonstrated that time spent engaging in home practice, as part of an eight-week MBSR course, was significantly related to the extent of improvements in mindfulness. Future research would benefit from exploring the relationship between level of practice performed and the degree of benefit obtained, in order to lend further support for this relationship.

Despite the improvements in general mindfulness and the specific facet of acceptance found within the current study, there were no significant changes in participants' perceptions of their ability to undertake values-based action in the face of unwanted internal experiences (e.g., anxiety, depression) at post-treatment, or at follow-up, compared with pre-treatment. One explanation for these findings is that there was a much larger focus, within the course, on developing the facets of mindfulness measured by the CAMS-R and the Acceptance subscale of the AAQ and a lesser focus on values based action. Whereas the attitudes of acceptance and non-judging, present focus, awareness of internal and external experiences and letting-go of unpleasant thoughts or feelings, were introduced at the beginning of the course (session 1) and emphasised and reinforced throughout the teaching components and mindfulness practices, the component on values-based action was not introduced until week five of the course. In relation to the findings immediately post-treatment, in retrospect, it seems unlikely that participants would have made substantial changes in this area one week later. However,

effect sizes within the small and medium range were observed for the Action subscale of the AAQ at post-treatment and at follow-up ( $d=0.49$  and  $d=0.56$ ), respectively, which might indicate a degree of improvement over the duration of the study. This might suggest that future research would benefit from including a larger component on values-based action, perhaps earlier in the course, in order to obtain greater improvements within this domain. Also, the slight increases at follow-up, relative to post-treatment (Table 3.3 & Table 3.4), might suggest that improvements within this domain will continue to occur over a longer period of time.

**5.1.2 Principle Hypothesis 2: Participants taking part in the MBSR course will report lower levels of anxiety and depression post-treatment and at 3-months follow-up than at pre-treatment.**

Participants exhibited significant improvements in both anxiety and depression levels immediately following the intervention and these were maintained three months later. This supports the idea that an intervention, designed specifically to increase mindfulness in parents of chronically ill children, can substantially improve emotional wellbeing. The findings relating specifically to anxiety and depression will be discussed in turn.

***Improvements in Anxiety in Relation to other Mindfulness-Based Research***

The magnitude of improvements in anxiety, at post-treatment and at follow-up, were broadly consistent with findings reported by the majority of standard eight-week mindfulness-based studies. For example, calculations based on the data reported by Minor *et al.* (2006), obtained from parents of children with various chronic conditions (medical diagnoses, mental health problems and learning disabilities), revealed a similar pre-post effect size ( $d=0.62$ ) for anxiety to that obtained within current study ( $d=0.54$ ), with both falling within the medium effect size range (Cohen, 1992). Findings from standard eight-week MBSR courses with anxious medical patients ( $n=174$ ) and adults



with various anxiety disorders ( $n=22$ ) also demonstrated pre-post effect sizes of  $d=0.61$  (Carmody and Baer, 2008) and  $d=0.87$  (Kabat-Zinn *et al.*, 1992), respectively.

Unfortunately Minor *et al.* (2006) did not publish follow-up data. However, Kabat-Zinn *et al.* (1992) demonstrated an effect size of  $d=0.95$  for anxiety at 3-months follow-up, suggesting that treatment gains observed post-treatment were not only maintained, but that participants continued to experience improvements in anxiety following the end of the course. There is also some evidence to suggest that treatment gains observed post-treatment can be maintained over much longer periods. Miller *et al.* (1995) collected three-year follow-up data on 18 of the original 22 participants involved in the study by Kabat-Zinn *et al.* (1992) and demonstrated that the statistically significant improvements in anxiety at post-treatment persisted three years later, with their data indicating an effect size of  $d=0.75$ .

To date, the vast majority of research involving MBCT has focused on either depressed or recovered, recurrently depressed adults. Relatively few studies have examined the potential benefits of this approach with anxious individuals. However, in view of the overlap between depression and anxiety symptoms, Eisendrath *et al.* (2008) measured anxiety before and after an MBCT intervention for treatment-resistant depressed adults and obtained a pre-post effect size of  $d=0.41$ . Finucane and Mercer (2006) also reported an effect size of  $d=0.77$  for anxiety three-months following an eight-week MBCT intervention, which was delivered to 13 patients with active depression and anxiety. Unfortunately the authors did not report an effect size for anxiety immediately following the intervention, which would have provided insight into whether the immediate treatment gains following the course were maintained.

Overall, the few MBCT interventions that have included a measure of anxiety have generally obtained similar improvements to outcome studies involving MBSR courses.

However, this is with the exception of MBSR studies that have specifically recruited individuals with anxiety disorders (e.g., Kabat-Zinn *et al.*, 1992), which have obtained larger effect sizes.

The specific role of mindfulness practice in bringing about change in psychological well-being has been demonstrated by Carmody and Baer (2008), who found that time spent engaging in home practice over an eight-week course was significantly related to the extent of improvements in participants' anxiety. However, it is less clear whether the inclusion of a teaching component on anxiety, around the themes of cognitive therapy, leads to specific benefits within this domain. With regards to the current study, it would appear that the teaching component, specifically focused on stress and anxiety, did not lead to greater improvements in anxiety, compared with standard MBSR courses. However, since this is the first time that this type of intervention has been delivered to parents of chronically ill children, for whom the nature of their anxiety might be somewhat different, it is difficult to make direct comparisons across studies.

Whereas anxiety disorders are generally characterised by an unrealistic or excessive concern about threat in the future (Hawton *et al.*, 1989), the worries of parents of chronically ill children might be more grounded in reality, including concerns about the progression of their child's illness or the impact of the illness on their child's quality of life (Moorey, 1996). In view of this, it might be that mindfulness-based interventions are particularly suited to situations wherein underlying problems are not resolvable, such as in the case of chronic medical conditions. Indeed, the improvements in distress observed in the current study occurred despite no apparent change in the underlying adversity experienced by participants (i.e., the children continued to suffer from chronic illnesses). Unfortunately the sample size restricted exploration of the relationships between mindfulness and parental psychological well-being, for example, whether improvements in acceptance are associated with improvements in anxiety, which would be an interesting area of future research.

In general, the findings obtained within the current study appear promising and consistent with other research in the field. This is interesting since both the duration of the course and the length of home-based mindfulness practice was reduced from that included in standard eight-week mindfulness-based courses. Also, similar to other studies that have included a follow-up measurement, participants within the current study continued to experience improvements in anxiety following the end of the course, which indicates, at least, short-term maintenance of treatment gains.

### ***Improvements in Depression in Relation to other Mindfulness-Based Research***

Following the intervention, depression scores dropped markedly ( $d=1.01$ ) and these improved even further, as measured at three months follow-up ( $d=1.21$ ). This was despite a slight increase in the median BDI value at follow-up, relative to post-treatment, which is likely to be an artefact of the use of parametric effect sizes with data that is more suited to non-parametric analyses. The small sample size and greater variability around the median at follow-up, relative to post-treatment may also have contributed to this discrepancy. Whilst this highlights a limitation of using both parametric and non-parametric methods for analysing the data, the author considered it to be important to include effect size calculations in order to determine the size of any changes. This issue is discussed further in section 5.3.5 of this manuscript.

This is consistent with standard eight-week mindfulness-based interventions, designed to specifically target depression, which generally draw on the MBCT course designed by Segal *et al.* (2002). For example, Kenny and Williams (2007) reported a similarly large pre-post ( $d=1.04$ ) effect size for depression following an eight-week MBCT course delivered to 79 adults with treatment-resistant depression. In addition to this, Eisendrath *et al.* (2008) obtained a large pre-post effect size ( $d=0.94$ ) for depression, following their eight-week MBCT intervention for people with major depressive disorder.

Unfortunately neither of these MBCT studies included a follow-up measure in order to determine the maintenance of treatment gains over time. However, Finucane and Mercer (2006) obtained a large ( $d=1.5$ ) effect size for depression, as measured three-months post-treatment (relative to pre-treatment), following their eight-week MBCT course for adults with active depression and anxiety.

The magnitude of improvements in depression within the current study and those involving standard MBCT courses are somewhat larger than those obtained by studies involving standard eight-week MBSR courses. For example, Minor *et al.* (2006) obtained a pre-post effect size of  $d=0.48$  and Kabat-Zinn *et al.* (1992) found an effect size of  $d=0.59$ . This might be said to reflect the nature of the difficulties experienced by participants within these studies, in that they were more highly anxious, at baseline, than depressed, thereby providing greater capacity for change in the former. However, Ramel *et al.* (2004) delivered an eight-week MBSR course to 23 adults with recurrent depressive disorder and found a similar pre-post effect size ( $d=0.52$ ) for depression.

Although the effect sizes for MBSR tend to be smaller than for MBCT, treatment gains following MBSR courses appear to be durable. For example, Kabat-Zinn *et al.* (1992) demonstrated an effect size for depression of  $d=0.95$ , three-months post-treatment, and Miller *et al.* (1995) extended these findings to show that these improvements were maintained three-years post-treatment ( $d=0.90$ ). These findings suggest that participants continued to experience improvements in depression following the end of the MBSR course and that these were maintained over a long period of time.

Considering the current study included the central elements of MBCT and that this type of approach was specifically designed for treating depression, it is perhaps unsurprising that this study and standard MBCT studies have obtained somewhat better outcomes on measures of depression than standard MBSR courses. In particular, the course within the current study dedicated specific teachings on depression, including considerable time

being allocated to discussions about the fundamental nature of the interrelationships among thoughts, feelings, physical symptoms and behavior, both in general and in the context of depression. Relapse prevention plans, based on cognitive behavioural models, were also consistent with MBCT.

### ***Comparison of findings with Alternative Treatment Approaches for Distressed Parents of Chronically Ill Children***

Existing interventions for parents of chronically ill children have generally found no significant improvements in parental psychological well-being (see section 1.6). The one study reporting significant improvements within this domain involved a community-based family intervention (Ireys *et al.*, 2001). Calculations, based on the data reported, revealed a pre-post effect size for anxiety ( $d=0.15$ ) that was substantially smaller than that found in the present study ( $d=0.54$ ) and there were no significant improvements in depression. Therefore, the findings of the current study appear to compare favorably with the wider body of research involving interventions delivered to parents of chronically ill children.

### ***Comparison of Findings with Established Treatment Approaches***

The findings of the current study also appear to be consistent with studies that have delivered well-established treatments, such as Cognitive Behavioural Therapy (CBT). Indeed, CBT has been recommended by the National Institute of Health and Clinical Excellence (NICE; 2004) as the psychological treatment of choice for anxiety. Lambert and Ogles (2004) reported mean effect sizes of five meta-analytic studies that reviewed controlled trials involving individual-based CBT for various anxiety disorders, including social phobia, panic and generalized anxiety disorder. Mean pre-post effect sizes were:  $d=0.45$  (Feske & Chambless, 1995);  $d=0.68$  (Gould *et al.*, 1995);  $d=0.70$  (Gould *et al.*, 1997a);  $d=0.74$  (Gould *et al.*, 1997b); and  $d=0.63$  (Taylor, 1996), as cited in Lambert and Ogles (2004).



There is a scarcity of meta-analytic studies that have investigated group-based treatments for anxiety, although individual studies have been conducted in this area. For example, Kush and Flemming (2000) delivered a 12-week group CBT program to 26 adults with mixed anxiety and depression and reported a pre-post effect size for anxiety of  $d=0.44$ . Unfortunately this study did not include a follow-up measurement. However, Ladouceur *et al.* (2000) conducted a controlled clinical trial investigating the effectiveness of group-based cognitive behavioural therapy for anxious individuals and calculations based on their data revealed a pre-post effect size of  $d=0.87$  and an effect size of  $d=0.56$  at six-months follow-up.

With regard to depression, Kush and Flemming (2000) reported an effect size for depression of  $d=0.90$ . McDermut *et al.* (2001) conducted a meta-analysis of 48 controlled studies investigating the effectiveness of various group psychotherapies for depressed individuals, comprising approaches recommended within the NICE guidelines (2004) for depression, such as cognitive therapy, behavioural therapy, cognitive behavioural therapy, psychodynamic group psychotherapy and interpersonal therapy. The authors calculated a mean effect size in order to determine the magnitude of change in depression across these studies and obtained a pre-post effect size (immediately post-treatment) of  $d=1.03$ , and an effect size at follow-up of  $d=1.18$  (which took place an average of 19.1 weeks post-treatment).

Overall, the findings of the current study are broadly consistent with other studies investigating the effectiveness of well-established treatments. This is promising since randomised controlled trials, which are considered to be the gold standard of research, often have strict exclusion criteria, which can draw the generalisability of the findings into question. Indeed, the current study endeavored to have few exclusion criteria in order to increase generalisability to clinical settings. Issues pertaining to the design of the study are further addressed in section 5.3.



### ***5.1.3 Hypothesis 3: Participants taking part in the MBSR course will report less difficulty associated with parenting post-treatment and at 3-months follow-up than at pre-treatment.***

Participants reported significantly less distress associated with their parenting role at post-treatment ( $d=0.47$ ) and the extent of this improvement increased substantially at follow-up ( $d=0.95$ ), relative to pre-treatment. A marginally significant increase was demonstrated for participants' perceptions of difficult interactions with their child ( $d=0.43$ ) at post-treatment, although this was not evident at follow-up. There were no significant differences at post-treatment or follow-up in terms of parents' perceptions of difficult child behaviours.

### ***Comparison of Findings with Alternative Treatment Approaches aimed at Reducing Perceived Difficulties associated with Parenting***

As far as the author is aware, this is the first study to have investigated the effectiveness of a mindfulness-based intervention in reducing parents' perceptions of the difficulties associated with their parenting role. However, the findings of the current study appear to compare well with other treatment approaches employed with parents of chronically ill children, in terms of reductions in the distress associated with parenting, although it compares less favorably in terms of parents' perceptions of difficult child behaviours. For example, Tew *et al.* (2002) did not find significant differences in parental distress following a Filial Therapy intervention delivered to parents of chronically ill children (as measured using the PD subscale of the PSI), yet found significant improvements in terms of parents' perceptions of their child's behavior (DC subscale).

One explanation for these discrepancies is that the intervention by Tew *et al.* (2002) focused on teaching parents skills to enhance the emotional and behavioural well-being of their child, rather than focusing upon reducing parental distress. However, since the participants within the study by Tew *et al.* (2002) did not report reduced parenting

distress, one might question whether these parents were able to continue to implement these skills within their parenting role following the end of the 10-week training course. Indeed, previous research has demonstrated that parenting distress is significantly related to impairments in parenting ability (see section 1.5.2). Unfortunately the authors did not include a follow-up measure to examine the maintenance of treatment gains.

Understandably, most studies that have investigated the effectiveness of interventions aimed at reducing parents perceived difficulties with their parenting role have focused upon parents who have children with high levels of behavioural problems. For example, Kazdin and Whitley (2003) reported findings of a 16-session combined problem-solving training and management-skills training intervention delivered to parents of medically healthy children, with aggressive and antisocial behaviour, and obtained a pre-post reduction in perceived child-related difficulties with an effect size of  $d=1.01$ . Their relative success in reducing parents' perceived difficulties may be due, in part, to the higher levels of pre-existing difficulties exhibited by the children in their study and also because the intervention focused upon improving the behaviour of the child rather than enhancing the well-being of the parent. Indeed, this study obtained a smaller pre-post effect size for reductions in parental depression ( $d=0.35$ ) than was obtained within the current study.

### ***Interpretation of Current Findings***

Turning first to discuss the observed improvements in parenting distress, one explanation for this finding is that there is a degree of overlap between general distress and parenting distress, with reductions in the former resulting in reductions in the latter. Indeed, research has demonstrated that maternal psychological symptoms, as measured by the Brief Symptom Inventory (Derogatis & Melisaros, 1983), accounted for 17 percent of the total variance of the parenting distress factor of the PSI-SF (Reitman *et al.*, 2002). Indeed, it seems reasonable to suppose that if a parent is suffering from

reduced psychological well-being, this may impact negatively on their perception of their role as a parent and/or their ability to carry-out parenting duties, leading to greater distress associated with this role. This relationship might be bi-directional in that greater distress associated with parenting might further exacerbate general distress.

A potential explanation for the apparent lack of improvement within the current study in terms of participants' perceptions of child behaviour problems is that relatively low rates of child behavioral difficulties were present at pre-treatment. Indeed, the median baseline score for the sample was not above the average based on normative data. One explanation for this is that the DC subscale is most strongly associated with externalising behavior problems in children (e.g., Cuccaro *et al.*, 1993; Donnenberg & Baker, 1993), whereas research has shown that emotional problems are more prevalent than behavioural problems among children with chronic illnesses (Glazebrook *et al.*, 2003). This issue is discussed further in section 5.1.4.

With regard to the increase in parents' perceptions of difficult parent-child interactions ( $d=0.43$ ), taking into account the significant increases in mindfulness among the sample at post-treatment, it may have been that participants were functioning less on automatic-pilot and, hence, more aware of their environment. This might mean that participants were also more aware of the difficulties that had become habitual within their interactions with their child, or as Dumas (2005) termed, ATP's. Also, since participants reported heightened levels of acceptance following the course, it might have been that they became more accepting of such difficulties, which would help to explain the reduction in parenting distress following the course.

Furthermore, reductions in parents' perceptions of difficult interactions at follow-up, relative to post-treatment, were reported (Table 3.7 & Table 3.8). This might suggest that changes in the nature of these interactions were beginning to take place. Indeed, it

would only be expected that participants would first become aware of difficulties within their interactions with their child, before beginning to change their own behavior in these interactions, which would then lead to changes in the nature of these exchanges. Therefore, this might suggest that further improvements within this domain will continue to occur over longer periods of time. Future research would benefit from including a longer follow-up period in order to explore changes within this domain over a longer period of time.

**5.1.4 *Hypothesis 4: Participants who take part in the MBSR course will perceive improvements in their child's wellbeing post-treatment and at 3-months follow-up, relative to pre-treatment.***

Participants did not perceive significant improvements in their child's wellbeing as a consequence of the intervention. As mentioned above, one possible explanation for these findings is that participants within the current study perceived relatively low levels of emotional and behavioural problems amongst their children at baseline. Based on the classification system for interpreting the SDQ scores (Appendix 11), the baseline median value for the Total Difficulties scale fell within the 'borderline' range, as did the median values for the Emotional Problems and Conduct Problems subscales. The median values at baseline for the remaining subscales (peer problems, hyperactivity/inattention) fell within the 'normal' range.

These findings were somewhat surprising, since it was postulated that those parents experiencing higher levels of distress (who would opt to participate in the study) would be more likely to have children with higher levels of emotional and/or behavioural problems, with these two factors (parental distress and child distress) interacting with one another. There are various possible explanations for these findings. Firstly, only three participants in the current study rated their children within the 'abnormal' range on the emotional problems subscale and this was true for only one participant in relation to the conduct (behavior) problems subscale. This is broadly consistent with findings from

the large scale study conducted by Glazebrook *et al.* (2003), which demonstrated that the proportion of chronically ill children scoring within the abnormal range on the emotional and conduct problems subscales of the SDQ were 26 percent and 19 percent respectively.

Another possible explanation for these findings relates to the sensitivity of the tool that was used to measure child well-being within this population. Mathai *et al.* (2002) demonstrated that the parent version of the SDQ reliably detected emotional and behavioural problems in a sample of children referred to a Child and Adolescent Mental Health Service. However, it is less clear whether this measure is suitable for detecting such difficulties at the less severe end of the spectrum, which raises questions regarding whether floor effects were observed within the current study. Matai *et al.* (2002) also demonstrated that correlations between emotional subscale scores on the child and parent versions of the SDQ were lower with younger children than with older children. Although this might have reflected lesser emotional insight among younger children within this study, it might suggest that participants within the current study, who had younger children, were also less able to accurately identify the presence of such difficulties within their children. Overall, Matai *et al.* (2002) reported that correlations between scores on the parent and child versions of the SDQ revealed moderate inter-rater agreement on the emotional ( $r = .515, p < .01$ ) and behavioural ( $r = .547, p < .01$ ) subscales. Therefore, although this is a useful general measure of child well-being, especially with children displaying higher levels of emotional and behavioural problems, the SDQ might lack sensitivity in terms of measuring these specific domains in children with relatively low levels of difficulties.

Another potential explanation for the observed findings pertains to the indirect approach that the current study undertook in order to change participants' perceptions of child-well being. Whereas other research studies have targeted interventions specifically to modify child behavior or improve the child's emotional well-being, the current study



aimed to enhance parental well-being, which was postulated to have a positive impact on parental perceptions of their child's well-being (see section 1.5.3 for a review of the literature). Therefore, although no significant improvements were observed in terms of child well-being at the different time-points, there were small but wide-spread improvements across the different subscales of the SDQ at follow-up, compared with post-treatment (section 3.5.2). This might be indicative of early improvements within this domain, which would be expected to follow improvements in parental well-being. Indeed, it might be that improved psychological well-being in parents alters their perceptions of their child's emotional or behavioural well-being, without leading to changes within the child. On the other hand, it might be that such improvements in participants enable them to demonstrate more effective parenting skills, thereby impacting positively on the well-being of their child. Whilst it was beyond the scope of the current study to explore these relationships, these are interesting areas for future research, which would help to identify the particular benefits that this type of intervention might have for chronically ill children themselves. Alternative methods for measuring child well-being in future research will be discussed in section 5.4.

## **5.2 Clinical Implications**

The Scottish Executive (2007a) stated their commitment to improving the quality of care that children and their families receive when accessing the NHS in Scotland. Various documents have highlighted the need for agencies to work together to ensure that children receive holistic care, which addresses their physical, emotional and social needs (Scottish Executive, 2001; Scottish Executive, 2005). As part of this care, it has been identified within the Better Health Better Care Action Plan (Scottish Executive, 2007b) that the impact of parenting and parental stress on the quality of care and interaction with children must be considered. In order to enhance quality of life in parents of chronically ill children and, potentially, the well-being of the ill child, it seems



paramount that research is directed towards identifying effective treatments for this population.

Although based upon a small sample, this study suggests that a brief MBSR course, tailored specifically for parents of chronically ill children, can enhance psychological well-being (reduce anxiety and depression) and reduce the distress associated with parenting. The observed improvements also appeared to be maintained three-months following the end of the course, which would seem to suggest that treatment gains are durable, at least in the short term.

The relatively high baseline scores for depression are also worthy of consideration. Indeed, since the intervention described within this study was advertised as a Mindfulness Based Stress Reduction course, it was postulated that this would mostly attract parents who were experiencing high levels of stress and anxiety. One explanation for the large number of participants with relatively high levels of depression relates to the well-documented co-morbidity between anxiety and depression (Melartin *et al.*, 2002; Sartorius *et al.*, 1996). Clearly there is considerable potential benefit for interventions that can alleviate stress, anxiety and depression.

Moreover, the current study found no evidence that significant levels of depression inhibited the effectiveness of the intervention, despite previous suggestions that MBCT (or MBSR) would not be suitable for currently depressed adults. Specifically, it was suggested that people who are actively depressed would find it too difficult to concentrate during the practices and to motivate themselves to comply with the home-based tasks (Williams *et al.*, 2007). However, the findings of the current study would lend support for the use of mindfulness-based approaches with individuals experiencing current high levels of depression. The present findings are also consistent with more recent research involving adults with active depression, which has demonstrated

significant improvements following standard MBCT courses (e.g., Eisendrath *et al.*, 2008; Finucane & Mercer, 2006; Kenny & Williams, 2007). Interestingly, the duration of home-practices was shortened in the current study in order to reduce the demands for busy parents. However, similar modifications have been made in other studies with actively depressed adults, such as Finucane and Mercer's (2006) study, which reported a large pre-post effect size for depression ( $d=1.5$ ).

Various factors also indicate the acceptability of this approach to the current sample. These include the low attrition rate, the apparent completion of home-based tasks (based on the five diaries returned) and findings from the Course Evaluation Questionnaire. Most participants reported that they found the course relevant to their situation and the material to have made sense (Figure 4.3). All participants also reported that that they gained from the course what they had hoped to gain and had managed to incorporate mindfulness skills into their daily lives (Figure 4.4).

The MBSR course outlined within the current study has the potential to offer a cost-effective solution to meeting the demands within healthcare services. Group-based treatments require less professional time, which means that throughput can be quicker and waiting times kept short. Indeed, studies have demonstrated that group-based treatments are substantially more cost-effective than individualised treatment approaches (Cunningham *et al.*, 1995). Research involving various different group and individual treatment approaches has also provided support for the comparable effectiveness of the two formats (Burlingame *et al.*, 2004; McRoberts *et al.*, 1998).

### 5.3 Strengths and Limitations of the Study

#### 5.3.1 Recruitment Process

Extensive efforts were made to recruit participants and various measures were taken in order to overcome some of the common barriers to recruitment, as documented within the literature. These include: a distrust of research; uncertainty regarding what the study would entail; a preference for 'treatment' rather than participation in clinical trials; lack of time; problems understanding the informed consent process; and lack of childcare (Daunt, 2003; Heinrichs *et al.*, 2005; Spoth *et al.*, 1996),

In particular, special care was given to ensuring that participants were fully informed about what their participation in the study would involve (e.g., highly informative leaflets and information sheets; opportunities to contact the principal researcher for further information; and a pre-group meeting, which partly included an opportunity to directly experience the type of practices that would be involved in the course). Participants' responses to the course evaluation questionnaire also indicated that they felt that they had been provided with sufficient information about the study prior to the course beginning, which would suggest that this aim had been achieved (section 4.2.3). The principal researcher also spent time with participants discussing the purpose and process of giving informed consent.

The MBSR course was arranged at a time (6.30-8.30pm) postulated to be most accessible for parents who had commitments during the day (e.g., work, childcare). Findings from the Course Evaluation Questionnaire (Figure 4.1) indicated that group-meetings were delivered at a time that was most suitable to all participants. However, these findings may be somewhat biased since it was most likely that those participants who took part in the course found it to be held at a suitable time. This is discussed further in section 5.3.2.

### 5.3.2 *Sample Size*

Despite these efforts, recruitment was relatively slow and far fewer parents came forward for participation in the study than was expected. A power calculation (section 2.8) revealed that a minimum of 12 participants were required for the study, and it was intended that significantly more than this would take part. This means that the study was insufficiently powered for medium or small effect sizes and, thus, may have been unable to statistically detect effects at this magnitude.

In view of the large number of parents with chronically ill children who were likely to have been suffering from significant psychological distress, the low recruitment rate warrants consideration. One possible explanation is that parents of chronically ill children who feel stressed may perceive themselves to have insufficient time to engage in a six-week course, given the large time-commitment required. Indeed, the very nature of stress itself is proposed to result from the perception that existing demands upon oneself outweigh ones' resources or ability to cope with such demands (Lazarus and Folkman, 1984).

In addition to this, from clinical experience, it is clear that many parents who have chronically ill children often feel a sense of guilt in relation to their child being chronically unwell and focus their attention and energy towards improving the life of their child, often to the expense of their own well-being (section 2.5.2). In view of this, parents may not have signed up to a course that was aimed to address their own needs.

Furthermore, unfortunately funding was not available to offer childcare, which might have restricted access to the course for some parents. Indeed, no single parents took part in the current study (section 3.1.1). This suggests that difficulty obtaining childcare might have acted as a potential barrier to those parents who were carrying sole parenting duties, especially since the groups were held in the evening time, at which point children

would have been home from school. This is an issue that certainly warrants attention in future studies, especially since single-parenting has been associated with higher levels of parental distress (Beckman, 1983) and since divorce and separation rates are increased among parents of chronically ill children, relative to families with healthy children (Jessop & Stein, 1989).

### **5.3.3 *Generalisability***

A strength of the current study is that the MBSR course was protocol driven, increasing the replicability of the findings. Also, although the sample recruited for this study was relatively small, participants reported a broad range of demographic variables, which helps to support the generalisability of the current findings to the population from which the sample was drawn. Specifically, participants were of a wide age range (28-47 years), had children with a variety of medical diagnoses, who were also from a broad age range (3-12 years) and who had been diagnosed between 3 months to 12 years prior to the course beginning (see Table 3.1 for the means and standard deviations for these values). However, we cannot assume that these parents are representative of other parents who have children with these conditions, either within the local area or from elsewhere in the United Kingdom. Indeed, the small sample size and spread of chronic childhood illnesses might have decreased the generalisability of the current findings to other parents with children who have specific diagnoses, such as diabetes, cystic fibrosis. A larger sample involving greater proportions of parents who have children with each medical diagnosis or a sample consisting of parents who have children with one specific diagnosis would enable an exploration of this issue and lend support for the effectiveness of the intervention with specific groups.

There was an equal distribution of parents within the current study in terms of employment, with half of the sample being employed (working part- or full-time) and the other the other half working as homemakers. However, only two males took part in



the study, which represents an unequal distribution of mothers and fathers. Indeed, this is a pattern that has tended to reflect the majority of research studies with parents of chronically ill children (Kazak, 1997). One potential explanation for this is that mothers have tended to play a dominant role as caregivers and have, thus, been more accessible to study (Cohen, 1999). The proportion of males taking part in the current study is also not out of keeping with many other studies that have employed mindfulness-based approaches (Baer, 2003). However, further research involving larger samples would be able to lend further support for the equal efficacy of the MBSR course for both mothers and fathers.

Also, since parents were essentially required to self-select, those who engaged in the study were likely to have been highly motivated, thereby increasing the likelihood of them engaging in the home-based practice and reducing the possibility of attrition. However, if the MBSR course was to be delivered as part of a clinical service, this would likely involve an assessment of parents' motivation to engage in view of the significant time commitment and home-practice required. This would potentially help to identify those parents who would be less likely to benefit from the course at an early stage.

#### **5.3.4 Design**

A substantial limitation of the present study was the absence of a control group. Indeed, it was initially intended that a waiting list control group would be included in the study. However, the slow recruitment process coupled with the restricted time for collecting the data meant it was not feasible to include a control condition.

Given the absence of a control condition, it is possible that improvements observed were a result of factors other than the intervention itself. These could include; maturation (e.g., improvements in the child's medical conditions), history (i.e., the influence of

events other than the intervention) and/or regression to the mean (Clark-Carter, 2004). However, other studies involving parents of chronically ill children have demonstrated that, in the absence of intervention, parental distress remains relatively stable over time. For example, Thompson *et al.* (1994) measured psychological distress in mothers of children with cystic fibrosis over a 12-month period, using the Symptom Checklist 90-Revised (Derogatis, 1983), and demonstrated minimal differences between means and standard deviations at baseline and at one year later ( $M=50.85$ ,  $SD=8.67$ ;  $M=50.46$ ,  $SD=8.94$ , respectively). In addition to this, Ireys *et al.* (2001) administered the anxiety subscale of the Psychiatric Symptom Index (Ilfeld, 1976) to 66 mothers of children with various chronic illnesses, including diabetes, sickle cell anaemia, moderate to severe asthma, and demonstrated that scores at baseline ( $M=19.2$ ,  $SD=2$ ) and then one year later ( $M=21.5$ ,  $SD=16.4$ ) remained relatively stable, with a slight increase in the mean value for the group.

A strength of the current study is that participants were administered the same measures at different time-points, which enabled an exploration of change over time. Specifically, the inclusion of a baseline measurement enabled participants to act as their own controls, with which subsequent changes could be compared. The inclusion of post-treatment and follow-up measures enabled the exploration of the maintenance of treatment gains over time. However, a longer follow-up period (e.g., 12 months) would have provided further support for the maintenance of treatment gains over a longer period of time. Indeed, previous studies have provided support for the maintenance of improvements following mindfulness-based interventions over much longer time periods, as discussed in section 5.1.2.

Another related limitation of the current study is the absence of a therapeutic or placebo comparison group. The inclusion of such conditions are not only important in order to determine whether new interventions are more, less or equally as effective as existing psychological therapies, but can help to control for nonspecific factors of mindfulness-

interventions, including therapeutic alliance, group support and relaxation. Indeed, within the Course Evaluation Questionnaires, participants detailed a range of non-specific benefits of the MBSR course, including factors such as 'the realisation that other people have similar thoughts/feelings/experiences to mine' (six participants) and 'taking time out each day' (four participants). Furthermore, since both course facilitators were trained and highly interested in mindfulness-based interventions, this might have accounted for a degree of variance in therapeutic outcomes. Indeed, the therapeutic orientation of the researchers has been found to account for approximately 10 percent of the improvement observed in clinical intervention research trials (Lambert, 2004).

In view of this, further research is required to provide support for the effectiveness of the active ingredients of the MBSR intervention. Still, the current MBSR study appears to have obtained greater improvements in psychological distress in parents of chronically ill children, compared with other published interventions which have included, what might be considered, some of the non-specific aspects of mindfulness interventions, including emotional support, social support and relaxation. In addition, as mentioned above, research is emerging that lends support for the specific role of mindfulness practice in bringing about improvements in psychological well-being (Carmody & Baer, 2008).

Moreover, since the principal researcher was involved in co-facilitating the MBSR course, there is a possibility of desirability effects, with participants' responses to the questionnaires reflecting aspects such as how they think the principal researcher may expect or want them to be feeling post-treatment. However, attempts were made to try to counteract such biases. For example, participants were informed that their responses were anonymous and were encouraged to respond as truthfully as they felt able to.

### **5.3.5 *Statistical Considerations***

An advantage of calculating effect sizes is that this estimation is independent of sample size, which allows the findings of related studies to be compared (Clark-Carter, 2004). However, as with any statistic calculated from a sample, the larger the sample the more accurate the statistic will be as an estimate of the value in that population, hence the more confidence we can place in the effect size (Clark-Carter, 2004). Therefore, as the sample involved in the present study was relatively small, we cannot draw firm conclusions that the effect sizes are representative of the population as a whole. This is because in small samples, outliers can have a dramatic effect on the outcome of effect size calculations. Also, since effect sizes were calculated using a parametric method, these should be regarded cautiously, as an estimate, since the current data may not have fulfilled the assumptions required for parametric statistics and the sample size was quite small.

The small sample size within the current study also limited the statistical analyses that could be conducted. A considerably larger sample would have enabled methods (e.g., path analysis or structural equation modeling) that could explore whether mindfulness mediates the relationship between parental psychological well-being (reduced anxiety/depression) and perceptions of child well-being and/or perceptions of difficult parent-child interactions. The relationships between these variables could be explored in future research with larger samples.

### **5.3.6 *The Current State of Mindfulness-Based Intervention Research***

Many of the limitations within this study are common among studies investigating the effectiveness of mindfulness-based interventions to date. For instance, most studies have not included a control or therapeutic comparison group and many studies have included small sample sizes (Baer, 2003). Therefore, although the existing research with regards to mindfulness-based interventions appears extremely promising, as with the current

study, these methodological limitations impact on the validity and generalisability of findings. However, defending the current state of research, Kabat-Zinn (2003) stated that research attempting to establish the effectiveness of a new intervention tends to be more descriptive and less methodologically rigorous initially. This allows early research to tentatively establish the value of new interventions and to serve as a foundation upon which more methodologically sound research can be established (Kabat-Zinn, 2003). This in mind, the current study provides support for the conduct of a larger controlled study to address these methodological limitations and to provide support for the findings obtained. Directions for future research that have arisen from the present study will be detailed below.

#### **5.4 Future Research**

In addition to a randomized controlled design, future studies would benefit from the inclusion of a longer follow-up period, in order to explore the long-term durability of the treatment gains observed within the current study. Indeed, in a recent Cochrane review, Durham *et al.* (2005) highlighted the value of longer-term follow-up assessments, demonstrating that over half of the participants (52%) within CBT trials for individuals with anxiety disorders or psychosis met the criteria for at least one mental health diagnosis at long-term follow-up (2-14 years).

In view of the potential limitations inherent in using parents as proxy measures of their child's well-being, future research might wish to use additional tools for measuring this, including child self-reports, observational measures, interviews or teacher-rating scales, in order to increase the likelihood of detecting changes within this domain. Also, in terms of parents' perceptions of the difficulties associated with their parenting role, the PSI-SF appeared to demonstrate some sensitivity to change (at least in terms of distress associated with parenting and possibly with perceptions of difficult parent-child interactions). However, future research might benefit from using the longer version of



the PSI (101 items), in order to further increase the likelihood of detecting change. It is, of course, a continuing challenge to select robust measures that remain accessible and that are not overly burdensome to participants.

Furthermore, given the recruitment difficulties within the current study, various additional measures may be taken to recruit participants. Firstly, a member of the research team might wish to attend parent support group meetings to explain fully the nature of the study and the MBSR course. This would also allow opportunities for parents to express their own personal barriers to participation, which could potentially be addressed by the research team. For example, it may be the case that it is necessary for funding to be obtained in order to offer childcare. Also, as parents might experience guilt in doing something to benefit themselves, these meetings would allow opportunities to emphasise to parents that enhancing their own well-being is likely to also help their child. These issues might be further addressed by involving both parents and their children within the course. Indeed, research is beginning to emerge which demonstrates the benefits of concomitant parent and child mindfulness training, at least for older children and their parents (Bogels *et al.*, 2008).

Various advantages of including a larger sample of participants in future research have previously been discussed within this manuscript. In addition to this, a larger sample would also increase the generalisability of the findings and enable an exploration of treatment gains in relation to specific participant variables (e.g., gender, parenting status, age, baseline severity of anxiety/depression) and illness variables, such as the stage of the illness (e.g., recently diagnosed, illness and symptoms being managed effectively, progression of illness, awaiting medical procedure and end stage of the disease).

Also, it is acknowledged amongst researchers in the field that it is currently uncertain whether individuals benefit from continued formal practice following mindfulness-based

interventions, in terms of the maintenance of treatment gains (Mark Williams, personal communication, 27th May 2008). Future research would, thus, benefit from developing a method for measuring formal post-course mindfulness practice, in order to investigate the relationship between this and post-course improvements. Measuring the extent and degree of mindfulness within everyday life is also methodologically problematic because of its internal subjective nature. Although it is proposed that measures such as the CAMS-R tap the outcome of this process, the role of informal mindfulness is worthy of future study. In particular, there is a need for the development of a reliable and valid tool for quantifying the degree of mindfulness that participants incorporate into their daily activities, which would enable future research to explore whether this is correlated with post-treatment gains. Finally, as treatment gains in anxiety were smaller than some eight-session mindfulness studies, and since the majority of participants (seven individuals) within the current study reported that they would have taken part in the course if it was eight weeks long, it seems appropriate to investigate the benefits of an eight session version of this course.

## **5.5 Conclusion**

This is the first study to have examined the effectiveness of a specially designed MBSR course for parents of children with chronic illnesses and the results obtained are promising. Whilst the sample size was small, the MBSR intervention demonstrated the potential to reduce anxiety, depression and parenting distress in participants. It is less clear whether this intervention can have a positive impact on parent-child interactions and on parents' perceptions of child emotional and behavioural well-being. Given the substantial impact that childhood chronic illness can have on the whole family, it is essential to identify effective approaches to alleviate distress and to increase quality of life among both parents and children who are coping with such adversities. The current pilot study offers the first step toward developing an evidence base for effective MBSR interventions for distressed parents and lends support for the conduct of a larger controlled trial.

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## **APPENDIX 1**

Poster Advertising the Study

A black and white photograph of a mountain valley. In the foreground, there are dark, silhouetted hills. In the middle ground, a calm lake reflects the light from the sky. A small town is visible on the right side of the lake. In the background, steep mountains rise up, with some peaks shrouded in mist or clouds. The overall atmosphere is serene and peaceful.

# 6-Week Stress Reduction Course

For Parents of  
Children with Medical Problems

A research study investigating the effectiveness of a specially designed 6-week stress reduction course.

If you would like more information about this course then please take a leaflet or contact Ms Corrie Darbyshire:  
tel: 01224 550139; email: [c.darbyshire@nhs.net](mailto:c.darbyshire@nhs.net)

## **APPENDIX 2**

Leaflet



## Further Information

If you would like to discuss any aspect of this course, including registering interest, then please contact:

Corrie Darbyshire  
Royal Aberdeen Children's Hospital  
Telephone: 01224 550139  
Email: [c.darbyshire@nhs.net](mailto:c.darbyshire@nhs.net)

In addition, there is a lot of information on the internet about mindfulness based stress reduction, in particular here:

<http://www.bangor.ac.uk/mindfulness/> and here:  
<http://www.umassmed.edu/cfm/>.

There is also a best selling book on mindfulness called: Full Catastrophe Living by John Kabat-Zinn. This is currently sold by Amazon for about £13.

## Registering Interest

If you would like to come along to our mindfulness based stress reduction course, then please contact Corrie Darbyshire as detailed above. She will arrange to meet with you, discuss more fully the nature of the course, and answer any questions that you have.

# Mindfulness Based Stress Reduction

A research study  
investigating the  
effectiveness of a 6-week  
stress reduction course for  
parents of children with  
medical problems.

Picture courtesy of Julie O'Donnell

## **APPENDIX 3**

### **Participant Information Sheet**

## Further Information

If you would like to discuss any aspect of this course, including registering interest, then please contact:

Corrie Darbyshire  
Royal Aberdeen Children's Hospital  
Telephone: 01224 550139  
Email: [c.darbyshire@nhs.net](mailto:c.darbyshire@nhs.net)

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If you would like to come along to our mindfulness based stress reduction course, then please contact Corrie Darbyshire as detailed above. She will arrange to meet with you, discuss more fully the nature of the course, and answer any questions that you have.

# Mindfulness Based Stress Reduction

**A research study  
investigating the  
effectiveness of a 6-week  
stress reduction course for  
parents of children with  
medical problems.**

Picture courtesy of Julie O'Donnell



## Background

Balancing the stresses and strains of everyday life and caring for children who have medical problems can be very demanding for many parents. At times it's natural to feel overwhelmed and to find yourself lost in thoughts about the past or worries about the future. Here at the Children's Hospital, we are going to run a course to help parents to develop their ability to handle the stress and worry that often goes along with bringing up children who have health difficulties.

Mindfulness based stress reduction courses have been running for about 30 years. During this time, many research studies have found that those who participate in these courses report a range of benefits. These benefits include:

- feeling more calm & relaxed generally & during difficult times
- more energy & enthusiasm
- improved feelings of psychological wellbeing
- reduced physical symptoms such as headaches, fatigue, muscular pain & those related to viral infections
- increased ability to deal with short-term & longer-term stressful situations

## The Course

The stress reduction course will be run as part of a research project. The courses will take place at different times throughout the year. So that parents who work or are otherwise busy during the day are able to attend, we will run the course on Tuesday evenings here at the Children's Hospital. It will consist of six sessions, each of which will last for between one to two hours. We will manage to offer a place to about 15 parents.

The course requires some commitment. As well as attending the classes, we will ask people to practise various skills for about 30 minutes, six days per week during the six-week course. We will encourage those who participate to develop their ability to:

- use helpful coping skills day-to-day
- feel relaxed and calm
- face the many problems life throws at us
- be more fully aware of the way that thoughts and feelings influence the way we behave
- find peace of mind in difficult situations and during periods of change

We will help you to try a variety of ways of developing the above life skills. Generally, the emphasis will be on practising skills rather than discussing them.

## **INFORMATION SHEET**

### **A RESEARCH PROJECT TO ASSESS THE EFFECTS OF A MINDFULNESS BASED STRESS REDUCTION COURSE FOR PARENTS OF CHILDREN WITH MEDICAL PROBLEMS**

You are being invited to participate in this research project because you have expressed an interest in attending a mindfulness based stress reduction course, which we are running as part of a research project.

Before you decide, it is important for you to understand why we are running this project and what participating will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

#### **What is Mindfulness?**

Mindfulness is the exact opposite of mindlessness or automatic pilot (the way in which we all get caught up with thoughts about this or that & lose contact with what is going on around us). Driving for miles on a motorway lost in our thoughts is a good example of this. Many parents, with children who have medical problems, often get lost in thoughts about the past or worries about the future. This can cause or maintain emotional difficulties such as stress, anxiety, low mood and depression. Mindfulness is a way of relating more helpfully to these kinds of thoughts and feelings and to what is currently going on in our lives generally. Mindfulness based stress reduction courses, which are a form of psychological therapy, have been running for about 30 years. During this time, many research studies have found that those who participate in these courses report a range of benefits. These benefits include:

- feeling more calm & relaxed generally & during difficult times
- more energy & enthusiasm
- improved feelings of psychological wellbeing
- reduced physical symptoms such as headaches, fatigue, muscular pain & those related to viral infections
- increased ability to deal with short-term & longer-term stressful situations

#### **What s the purpose of this course?**

We are running this course because we know that many parents of children with medical problems have significant levels of stress, anxiety and depression. We also know that children with medical problems can struggle at times and this shows itself as emotional and behavioural difficulties. Significant levels of stress, anxiety or depression in parents means it is even harder for them to deal effectively with even



the day-to-day challenges of bringing-up children, never mind the increased complexity of life with a child who has medical problems. In addition, we know that if we can successfully lower stress and anxiety, or raise low mood in parents, then this not only improves the emotional wellbeing of parents, but also the psychological wellbeing of their children. Therefore, we want to find out what are the effects of delivering this kind of programme to parents of children with medical problems, on the psychological wellbeing of both the parents and their children.

### **Do I have to take part?**

No. Participation in this project is entirely voluntary. Neither your future care nor your child's future care at this hospital or elsewhere in the NHS will be affected by your decision. You are free to withdraw from this project at any time.

### **What will I have to do if I choose to take part?**

If, after you have met with a member of the project team, you still wish to take part, then we will agree with you which one of the courses (that will run at different times of the year and perhaps if need be at different times of the day) would be best for you to attend. We will ask you to complete a small number of questionnaires, before the course; midway through the course; just after the course, and three months after the course. This is so that we can find out if the mindfulness based programme is helpful to parents and/or their children and if so, in what ways. One of these questionnaires asks you about the wellbeing of your child. We will not contact your child or seek direct information from him or her as part of this study. We ask only for your opinion on your child's wellbeing. So that we have a record of your permission to take part in the study we will ask you to complete a written consent form. Only Corrie Darbyshire (trainee clinical psychologist) and Dr Andrew Keen (chartered health psychologist) will have access to your questionnaire data. Details of what the course entails are presented below under "The Course". If you choose not to take part, you do not have to do anything further.

### **The Course**

We are offering a six-week mindfulness based stress reduction course. You will be asked to attend a group meeting once per week for about two hours. You will also be asked to practise skills at home in-between meetings. Typically the home practice will take about 30 minutes and we ask you to do this each day, for six days of the week, for the duration of the course. The aim of the course is to increase participants' ability to practice mindfulness day-to-day and in doing so also to improve their quality of life. Before you start the course, you will get the opportunity to meet Ms Corrie Darbyshire who will take you through one mindfulness exercise so that you can more fully understand what the course is about. She will also answer any questions that you might have.



**What are the possible disadvantages of taking part in the project?**

As you will not be given any medication and the only measures we will be taking involve completing questionnaires, we do not anticipate that you would suffer any adverse effects from taking part in the project. However, if during this course you think it would be helpful to meet with the course facilitator, for example, because you are finding aspects of the course emotionally difficult, then please let him know either at the beginning or end of the meetings (he will be available for at least 30 minutes either side of the meeting); by telephone or by email. He will arrange to meet with you as soon as possible at a time which suits you.

**What are the possible advantages of taking part in the project?**

If the treatment is beneficial we would hope that you would have an improved sense of wellbeing and quality of life. We also hope that you would observe an improvement in your child's behaviour and wellbeing. However, this cannot be guaranteed.

**What if new information becomes available?**

If new information about the effectiveness of mindfulness-based intervention programmes becomes available during your participation in this project, then the course facilitator will let you know about it and discuss with you whether or not you would like to continue taking part.

**What happens when the project stops?**

These programmes are part of a research project so we do not know if they will continue once the project has been completed. Mindfulness programmes are run all over the world and are often run for 6 to 8 weeks. However, during the last meeting we will discuss how to go about continuing with any new ways of coping that you have found useful. Any tapes, CDs and information sheets will be yours to keep. Also, if at the end of the mindfulness based stress reduction programme you would like to discuss how to obtain further help for emotional problems, then the course facilitator will arrange to meet with you as soon as possible.

**What if something goes wrong?**

If you are harmed by taking part in this project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

**What happens to any information collected about me?**

If you take part in this project then we will, with your agreement, notify your general practitioner. However, only members of the project team (Ms Corrie Darbyshire and Dr Andrew Keen) will have access to the psychometric data we collect about you. This will be stored on a password-protected computer and in a locked cabinet. Corrie

Darbyshire and Dr Andrew Keen will also be the only people who are aware of the material you discuss during the mindfulness course unless you indicate otherwise.

### **What will happen to the results of this project?**

This research project is being undertaken as part of the requirements the doctoral training programme in Clinical Psychology which is run by the University of Edinburgh. Consequently, the results will be presented in a thesis. In addition, we may try to publish the results in a scientific journal and may present our results at scientific and professional meetings, so that other professionals are aware of our findings. We will ensure that any information that might identify specific participants will not be included in any presentation, report or publication. The results will also be used to inform the nature and content of clinical services offered by the Paediatric Liaison Team, which is part of the Child & Family Mental Health Service based at Royal Aberdeen Children's Hospital. This team delivers a psychological service to children and their families who have difficulties relating to medical problems.

### **Who is funding this project?**

This project is being funded by the University of Edinburgh.

### **Who has reviewed the study?**

A panel of academic staff at the University of Edinburgh have reviewed our project. In addition, the North of Scotland Research Ethics Committee also reviewed our proposal in detail.

Thank you for considering to take part in this project. Should you have any further questions please contact one of the following:

Ms Corrie Darbyshire

Tel 01224 550139

Email: [c.darbyshire@nhs.net](mailto:c.darbyshire@nhs.net)

Dr Andrew Keen

Tel: 01224 550139

Email: [Andrew.Keen@arh.grampian.scot.nhs.uk](mailto:Andrew.Keen@arh.grampian.scot.nhs.uk)

## **APPENDIX 4**

Consent Form

Centre Number::  
Study Number:  
Patient Identification Number for this trial:

## CONSENT FORM

**Title of Project:**

**A Research Project to Assess the Effects of a Mindfulness Based Stress Reduction Course for Parents of Children with Medical Problems**

Name of Researcher: Ms Corrie Darbyshire (Trainee Clinical Psychologist)

**Please initial box**

- |   |  |                          |
|---|--|--------------------------|
| 1 | I confirm that I have read and understand the information sheet dated ..... (version .....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2 | I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.   | <input type="checkbox"/> |
| 3 | I agree to my GP being informed of my participation in the study.  | <input type="checkbox"/> |
| 4 | I agree to take part in the above study.   | <input type="checkbox"/> |

\_\_\_\_\_  
Name of Patient

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person taking consent  
(if different from researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## **APPENDIX 5**

Course Manual



# **MINDFULNESS**

## **COURSE**

### **MANUAL**

Child & Family Mental Health Service  
Royal Aberdeen Children's Hospital  
Westburn Road  
Aberdeen

## CONTENTS

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## **An Autobiography in Five Chapters**

*By Portia Nelson*

### **Chapter I**

I walk down the street.  
There is a deep hole in the sidewalk.  
I fall in.  
I am lost...I am helpless.  
It isn't my fault.  
It takes forever to find a way out.

### **Chapter II**

I walk down the same street.  
There is a deep hole in the sidewalk.  
I pretend I don't see it.  
I fall in - again.  
I can't believe I am in this same place.  
But it isn't my fault.  
It still takes a long time to get out.

### **Chapter III**

I walk down the same street.  
There is a deep hole in the sidewalk.  
I see it is there.  
I fall in...it's a habit...but, my eyes are open.  
I know where I am.  
It is my fault.  
I get out immediately.

### **Chapter IV**

I walk down the same street.  
There is a deep hole in the sidewalk.  
I walk around it.

### **Chapter V**

I walk down a different street.

Mindfulness means  
deliberately paying  
attention in a particular  
way in the present moment  
without judgement

## INTRODUCTION

This manual is designed to accompany the six-week mindfulness course run by the Child & Family Mental Health Service in Aberdeen. You will find that we describe in this manual what in very broad terms we will be doing from one week to the next.

### Home Practice

Mindfulness is very much a practical skill. You will learn far more about mindfulness by practising at group meetings and at home, than by reading about it. So, practising at home is an important aspect of this course. It is also important because we are trying to change ways of thinking and reacting to life events that have often long since become habits. It usually takes a lot of effort to learn new ways of living our lives. It will no doubt be tough trying to make time six days per week and there will be days when you don't much feel like doing it anyway. Do your best to find the space and you may well find that it will be worth it.

### Approaching the Course

The best way to approach this course is to think "I'll just have a go and see what I think of this stuff at the end of the six weeks." That way you aren't expecting immediate substantial improvements in every aspect of your life, nor are you so negative that you've defeated yourself before you begin. If you come along and engage in the course for six weeks, you'll be in a very good position to decide whether or not this approach might be helpful to you as you go about your daily life in coming months and years.

### Difficulties

This course is designed to help people more effectively deal with the problems that life throws at us. One way this is achieved is by encouraging people to live more fully in the present moment. Typically, this results in people reporting various benefits such as being more energised, happier, calmer, and more engaged with life. However, this approach to life also means acknowledging and being more in touch with our difficulties as they occur, rather than trying to turn away from them. In the medium and longer-term, people find that facing problems is more effective than avoiding them. Our mindfulness course will try to help you learn gentle ways of doing this.

## Confidentiality

This course is designed so that we discuss our experiences of mindfulness as we go along. It is one of the ways in which we develop our mindfulness skills. So, we talk about our personal experiences after practicing in the group, and when we discuss our home practice. Sometimes people might wish to disclose sensitive information. We would ask you to please be respectful to your fellow group members and to not discuss shared information outside the group.

## Course Aims

This course is essentially an intensive training programme. The overall aim is to help you to develop skills which might help you better look after yourself and increase your overall wellbeing. As indicated previously, we will do this by developing our mindfulness skills.

During the early parts of the programme there will be a lot of emphasis on raising awareness of what occurs in our minds and our bodies from one moment to the next. We will do this by practicing various mindfulness exercises together and at home. Later in the course, we will concentrate more on applying our learning to everyday life, and in particular to more challenging aspects of our lives. Again, we will do this by practising and exploring various mindfulness exercises.

As best you can, try to remember that this course is designed to develop and harness the resourcefulness that is already inside you.



## WEEK 1

### Home Practice

1. Do the body scan 6 days out of the next 7.

### Automatic Pilot

Sometimes we can drive our cars for miles lost in our thoughts without really being aware of what we are doing. This is called being on automatic pilot. Most of us live at least some of our lives in automatic pilot, especially as we get older and the newness of life experiences becomes somewhat blunted. We are miles away from what is actually happening in the present moment.

When we are on automatic pilot we tend to just drift off to wherever our thoughts take us. This can mean for example that we have imaginary arguments that might never occur, or that we return to difficult aspects of our past that we cannot change. It can seem like our moods change for the worse for no apparent reason. At these times we tend to get stuck in ways of thinking, and tend to react to what is going on in our lives, in ways that are often unhelpful.

Old habits like unhelpful ways of thinking and reacting to life events can be hard to break. The first step is to become more aware of our thoughts, emotions and bodily sensations from one moment to the next. This creates some space in which we can begin to make choices about how we behave: we can start stepping out of automatic pilot.

### The Body Scan

At our first meeting, we will practice a mindfulness exercise called the body scan. This involves moving the focus of our attention around the different parts of our body in a slow and deliberate way.

As you do the body scan, you will generally begin to notice that you have thoughts about all kinds of things. This might include thoughts about very mundane things that happened in the past, or perhaps significant worries you have about what your future might be like. Having intrusive thoughts is normal and the aim of doing the

body scan exercise (or any mindfulness practice) is **NOT** to have a blank mind as you move your attention around your body.

The idea is to begin to notice your thoughts arise and then as best you can let them go. So, we try not to get caught up in our thoughts. Of course, some more will come along soon to distract us again (sometimes the same ones), but that is just the brain doing what the brain does: bubbling away, producing thoughts and linking them to other things. How quickly you manage to notice that you have drifted away into your thoughts about this or that will vary. Also, you will notice that sometimes you have more distracting thoughts than at other times. This is just what happens, so try not to give yourself a hard time about it.

Try to:

- Not think in terms of success and failure
- Let go of ideas about what this might or might not achieve for you
- Just do it regardless of what happens - it doesn't matter if you fall asleep or lose concentration and so on. These are just experiences - try to be aware of them
- Not deliberately push thoughts away - this will make them come back even more especially if they are uncomfortable in some way. Best to let them just drift away and re-focus on your body. You might find it useful to label your thoughts in a way that's meaningful to you ("work", "judgement", "family" etc)
- Just accept the feelings that you have in your body whether they are pleasant, unpleasant or neutral - do your best to not want things to be different

## WEEK 2

### Home Practice

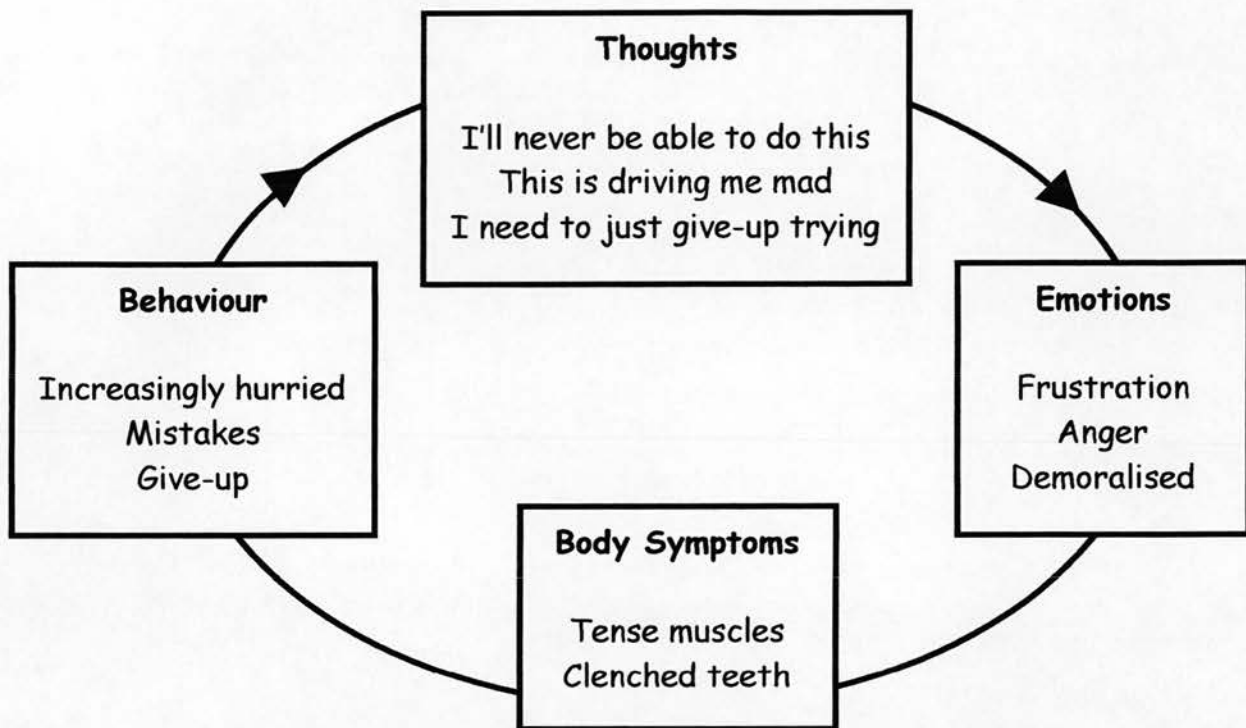
1. Do the body scan 6 days out of the next 7.
2. Choose one routine daily activity and try to bring moment-to-moment awareness to that activity each time that you do it. Examples include brushing teeth; showering; eating; waking up, and so on.

### Thoughts, Emotions, Body Sensations & Behaviour

Thoughts, emotions, sensations in our body and the way we behave almost always go together. So, for example, we rarely have happy thoughts when we are feeling thoroughly miserable, and *vice versa*. Psychologists tend to separate them as in figure 1, but for many people they are all part of the same experience.

Often thoughts and emotions interact in complex ways. Particular thoughts can lead to specific emotions, for example, if a parent interpreted a doctor's behaviour in certain ways which resulted in the thought **"This doctor isn't listening to me; he's not answering my questions"** then this could easily lead to the emotion **frustration** or perhaps **anger**. This kind of thing occurs all of the time in everyday situations too, but often we are not especially aware of it because the emotions resulting from our thoughts are typically less intense than the example above.

Just to make things even more complicated: when we already have certain emotions present, this tends to mean we are more likely to have thoughts or memories that go with these emotions. So, if we are already feeling frustrated or irritated (perhaps because we have had a bad day at work or at home), then we will more easily interpret (think about) situations later in the day (say our partner's behaviour) as frustrating or irritating. In addition, we will more easily recall occasions in the past when we think people have gone out of their way to be irritating toward us.



**Figure 1** An example of the relationships between thoughts; emotions; behaviour, and body symptoms.

You might have noticed that we have used words like "interpret" and "think that". This is deliberate and reflects the fact that there are many ways to interpret situations; what other people say and do, and even our own thoughts. That's why so many people who have experienced the same thing, say a football match or a wedding, have so many different ideas about what has just happened.

You will know by now, if you didn't beforehand, that the brain bubbles away producing lots of thoughts about this and that. The job of your brain is to protect you from danger and help you to survive. The way that it does this is by constantly categorising present events; relating them to past and possible future events, and working out what might be the best next action. Human brains have been doing this for thousands of years and it is unlikely that they will stop anytime soon. Like it or not, you have a thought and image generating machine in your head relating one event to another from the moment you open your eyes in morning until the moment you close them at night.

For lots of different, sometimes complicated reasons we tend to cling to some thoughts, and not to others. We think some thoughts are meaningful and others less so, and some thoughts just happen to push our buttons (often because they bring-up intense emotions). The result can be a shift in our mood for the worse. An example might be thoughts passing through our mind about an incident that happened say yesterday or last week when we thought that someone talked to us disrespectfully. Before we know where we are we can be imagining all the possible outcomes of telling the person what we think of him / her, and then what he / she might say back and so on and so on.... Needless to say we can find ourselves back there soon enough getting more and more worked-up....frustrated, angry, irritated, unhappy.....

Mindfulness is about stepping back from our thoughts; creating a distance and relating to thoughts in a different way. So, we try to see thoughts for what they are...just thoughts, mental events. They are not necessarily telling us anything truthful about ourselves; our loved ones or other aspects of the world; the past, or the future.

As best you can, try to bring your mindfulness skills to your thoughts:

- Don't push them away
- Don't cling to them
- Notice them, label them if it is helpful to do so, then gently let them go

Try to remember that:

- **Thoughts are not facts**
- **You are not your thoughts**

<p>"Man is troubled not by events, but by the meaning he gives them" <b>Euripides</b></p>
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## If I Had My Life to Live Over Again...

*By Nadine Stair*

"If I had my life to live over again,  
I would try to make more mistakes next time...  
I'd try not to be so perfect;  
I'd relax more, I'd limber up,  
I'd be sillier than I've been on this trip;  
In fact, I know of very few things I'd take quite so seriously;  
I'd be crazier ... and I'd certainly be less-hygienic;  
I'd take more chances ... I'd take more trips ...  
I'd climb more mountains ... I'd swim more rivers ...  
And I'd watch more sunsets;  
I'd burn more gasoline,  
I'd eat more ice cream - and fewer beans;  
I'd have more actual troubles and fewer imaginary ones,

You see, I was one of those people who lived prophylactically and sensibly,  
hour-after-hour and day-after-day;  
Oh, that doesn't mean I didn't have my moments,  
But if I had it to do all over, I'd have more of those moments,  
In fact, I'd try to have nothing but wonderful moments, side-by-side.

I was one of those people who never went anywhere without a thermometer,  
a hot water bottle, a gargle, a raincoat and a parachute;  
If I had it to do all over again, I'd travel lighter next time.

If I had my life to live all over again,  
I'd start barefoot earlier in the spring  
and I'd stay that way later in the fall;  
I'd play hooky a lot more;  
I'd ride more merry-go-rounds, I'd pick more flowers,  
I'd hug more children,  
I'd tell more people that I loved them,  
If I had my life to live over again;  
But, you see, I don't."



## WEEK 3

### Home Practice

1. Do the breathing practice 6 days out of the next 7.
2. Complete the pleasant and unpleasant events diary on alternate days
3. If you can, try to continue carrying out one daily activity mindfully

### Stress

Stress involves changes in our thinking, emotions, physiology and behaviour. There is a biological basis for these changes, namely the release of stress hormones such as adrenalin; nonadrenalin, and cortisol.

Stress can be a very intense short-lived, often very frightening experience. This is called the Fight or Flight Reaction and usually last for up to about 20 minutes. The release of stress hormones in this instance can cause many changes in our body, as detailed in figure 2, however, not everyone experiences all these symptoms. It is our body's way of helping us very quickly to escape from serious threats, or if this is not possible then helping us fight for our survival. This biological response was helpful when we wandered the African plains and had to escape very quickly from lions and other predators. So, stress is largely a response to threat, and this can be real (being chased by lions) or imagined (thinking about a possible disaster in the future, which may or may not happen).

Nowadays, stress tends to be considered a problem when it is on-going. Typical causes of stress include: work-related problems; bringing-up children; relationship difficulties; poverty, and caring for ill family members (especially children). But different people find different things stressful. If we are under stress for long periods of time then the levels of stress hormones circulating in our bodies reset to higher than normal levels. Among other things this often means that even when we first wake-up in the morning we have raised amounts of cortisol making us susceptible to intense negative emotions (anxiety, anger, frustration, irritability, apprehension and so on) throughout the day.

On-going release of high levels of stress hormones can cause health problems. These include:

- Increased deposits of fat in blood arteries
- Higher blood pressure
- Decreasing the functioning of the immune system so leaving people more vulnerable to infection and less able to heal wounds
- Muscular tension and headaches
- Bowel problems

**Stress and anxiety are inevitable consequences of living.** It is hard to imagine living a full and interesting life without experiencing stress. Generally, it is our efforts to cope with stress and anxiety that lead to life becoming increasingly difficult. Some ways of coping are naturally very attractive because they seem in the short-term to be effective but prove less than helpful in the medium and longer-term. Extensive efforts to control (rather than accept) anxiety and stress are almost always ultimately unhelpful and end-up causing problems elsewhere in life (often in our relationships with others).

### ***Avoidance***

This method of control involves not doing those things that lead to experiencing the uncomfortable symptoms of anxiety and stress. So, people are trying to avoid physical sensations; unpleasant thoughts; negative emotions, or any combination of these. In everyday life this typically means avoiding situations, people, and activities (e.g., social events; intimacy; flying; going out of the family home); being very vigilant for signs of possible danger; creating as much order as possible; going to bed; excessive alcohol and drug use, and various other strategies which may include distraction, in order to stop uncomfortable experiences occurring.

## *Escape*

This method of trying to control anxiety and stress refers to explicit attempts to get away from whatever is causing us unpleasant feelings. So, the goal of avoidance is that something does not occur, whereas the goal of escape is that something that has started to occur stops (quickly). Common ways that people use to escape from the uncomfortable symptoms of stress and anxiety include leaving a situation (social event, public place, work); using medications or alcohol; adopting idiosyncratic behaviours such as counting and cleaning; suppressing thoughts, and daydreaming.

Stress and anxiety are characterised by a certain style of thinking namely worry, which is future-orientated. Anxious people are worried about things going wrong at some point in the future. So, although stress and anxiety have a significant biological component (stress hormones), it is typically the way people think about their lives, and interpret events, that trigger the release of these chemicals. Basically, people judge that their ability to cope falls short of what is required to deal effectively with the problems they face. Almost always, people who are continually stressed or anxious overestimate threat and underestimate their ability to cope

Because people are different and find dissimilar things stressful, you can have stressful (or worrying) thoughts about almost anything. They are rarely about lions and other predators anymore. For many people, worrying thoughts get stuck. That is, the same kinds of worrying, stressful thoughts go around and around in their minds for long periods of time, especially at quiet times (laying in bed for example). Some examples are:

- "This piece of work I'm doing isn't good enough, I'm going to get the sack"
- "If I don't do everything for him, then he'll leave me"
- "If I don't worry about things, they definitely will go wrong"
- "I must plan for everything that might go wrong, just in case"
- "It is entirely my responsibility to make sure my child is well and if I don't focus completely on this, then bad things might happen"

Stressful and worrying thoughts are like any other thoughts - they might mean something or they might not. It is best to treat them like other thoughts. That is, try to notice them when they come-up; name what the thoughts are about if you

find this helpful; try not to push them away (they will come back even more frequently), and finally try to let them go.

### Mindfulness of Breathing

The second practice that we will do together is called mindfulness of breathing. In this exercise, we follow our breath as it flows in and out of our body. Generally, we do this practice sitting-down, say on a chair, although you can do it lying down too.

The process is:

1. Adopt an upright, dignified and relaxed posture, with your head very slightly tilted down so that your eyes fall on the ground several feet in front of you.
2. Close your eyes and focus your attention on those areas of your body that are supporting your weight. If you're sitting down on a chair, this usually means your feet and your bottom.
3. Focus your attention on your breath trying your best not to change it in anyway - just watching it flow in and out of our body.
4. Focus on an area where you can feel the flow of your breath - for most people this is the belly - the rise and fall of the abdomen.
5. Begin counting your out-breaths - 1, 2..... Go back to 1 if you lose count or when you reach 10. Carry on for about 7 minutes
6. Let go of counting exhailes and begin counting your in-breaths - 1, 2..... Go back to 1 if you lose count or when you reach 10. Carry on for about 7 minutes
7. Stop counting and just follow the flow of air in and out of your body.

Our breath is with us from the moment we come into the world until the day we die. We can use it as an anchor at almost anytime. If we find ourselves lost in thoughts about this or that, perhaps caught-up in quite emotional musings about the past or future, we can focus our attention on our breath.....at traffic lights;

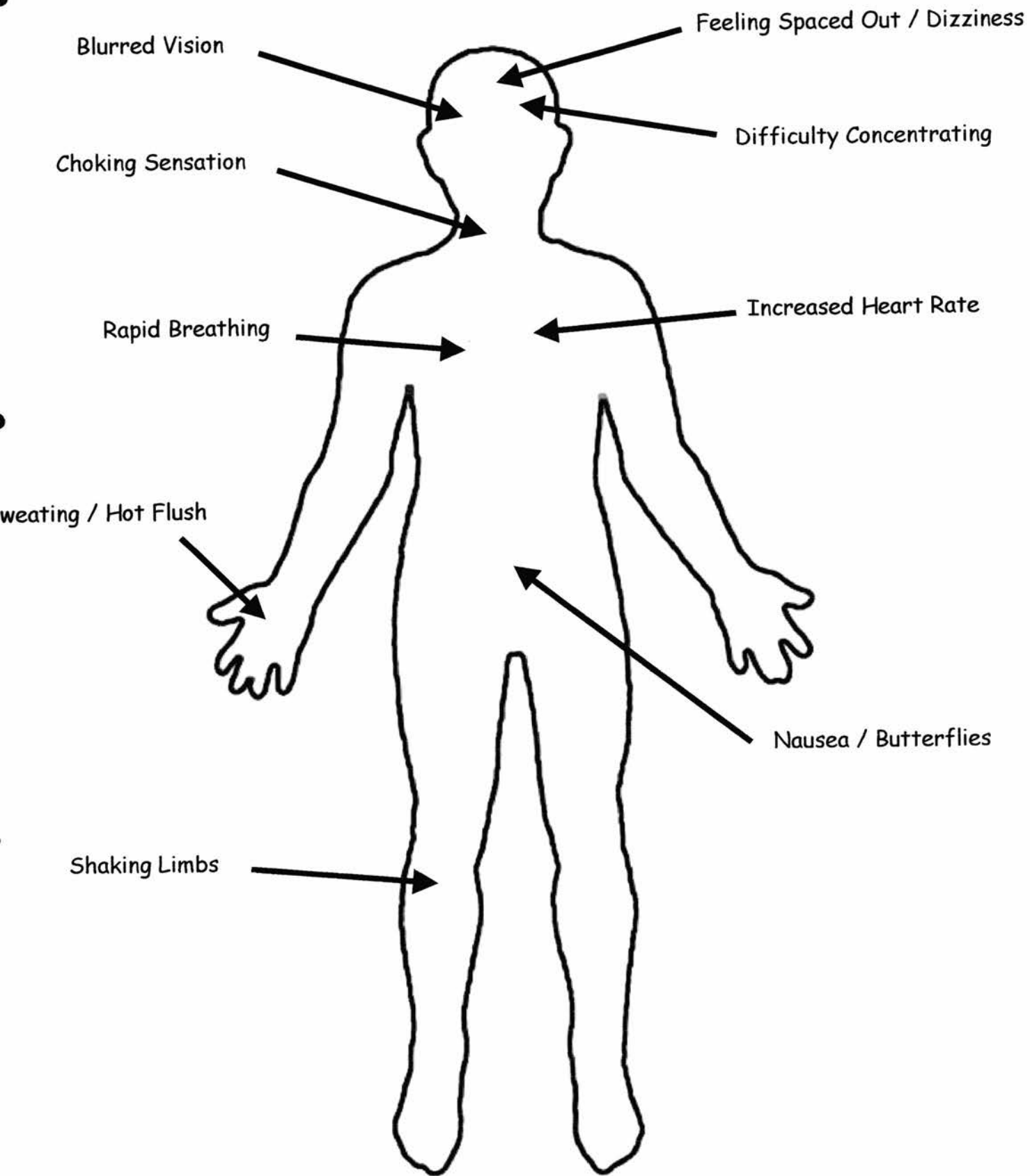
walking along the road; taking a few minutes sitting in a chair; looking out the window of a car or train etc. etc.

Like doing the body scan, you will notice thoughts about lots of different things, various emotions (may be boredom for example) and certainly body sensations. **This is normal.** Your job is to try to notice these experiences as soon as you can and the way they pull you away from your breath. Then, as best you can just try to let them go and return to your breath.

### Happy the Man

*By John Dryden*

Happy the man, and happy he alone,  
He who can call today his own:  
He who, secure within, can say,  
Tomorrow do thy worst, for I have lived today.  
Be fair or foul or rain or shine  
The joys I have possessed, in spite of fate, are mine.  
Not Heaven itself upon the past has power,  
But what has been, has been, and I have had my hour.



**Figure 2** Physiological changes due to sudden release of stress hormones



**PLEASANT EVENTS DIARY**

Try to be aware of pleasant events as they occur and write down one example at the end of the day.

Day	Situation	Thoughts	Emotions	Body Sensations

UNPLEASANT EVENTS DIARY

Try to be aware of unpleasant events as they occur and write down one example at the end of the day.

Day	Situation	Thoughts	Emotions	Body Sensations

## WEEK 4

### Home Practice

1. Do the breathing practice 6 days out of the next 7.
2. Do the breathing space practice at least once per day six days out of 7
3. If you can, try to continue carrying out one daily activity mindfully

### Depression & Low Mood

Most of us experience periods of relatively intense sadness in our lives. Often these feelings are linked to difficult life events such as the death of someone we love; losing a job; becoming less able to do some of the things we enjoy in life perhaps because of illness, or the breakdown of an important relationship. Changes in the wellbeing or potential wellbeing of our children can also trigger these types of feelings. So frequently we are having natural reactions to a sense that our lives will not be same again - something has changed for the worse.

Depression is more than sadness, but is also commonly associated with the types of events listed above. Typically, sadness is present but there are also many other experiences that go along with it. Some of these reflect changes in basic human biological functioning, for example:

- A change in eating habits - usually a decrease in appetite
- Sleep disturbance - problems getting to sleep and early waking
- Lack of interest in sex
- Loss of energy - feeling tired &/or easily becoming tired
- Trouble concentrating

Some of the other common signs of depression reflect the way we think, feel emotionally and behave, for example:

- Loss of interest in doing things we used to enjoy
- Reduced interest in socialising
- Feeling sad, worthless, and guilty
- Thinking that life is bleak and won't get any better
- Reduced self-confidence and self-esteem
- Low levels of motivation

As described previously, stress and anxiety are characterised by a thinking style called worrying, which tends to be about future events going wrong. Depression on the other hand, is characterised by a thinking style called **rumination**. This refers to generally bleak thoughts going around and around, which generally are about the past and about our various failings. Importantly, this style of thinking does not lead to resolution of problems and therefore serves no useful purpose, although for those experiencing these types of thoughts, it's often difficult to notice this is the case.

One of the things that we have found out following many years of research is that ruminating often drives people from the sadness that we all unavoidably feel during our lives into depression. It also seems to be the case that rumination prolongs the misery. That is, this style of thinking keeps the depression going.

We know that many parents caring for ill children have significant levels of depression. Some of the natural effects of depression (and low mood) can cause particular problems for parents, for example:

- Disturbed sleep and reduced energy levels can mean it becomes very hard for parents to find the resourcefulness to care for their family in ways that they expect of themselves

- Low confidence and a negative style of thinking can mean that parents often judge harshly their skills (and sometimes those of others) and so they undermine their often substantial efforts to care for their family
- Reduced socialising cuts parents off from important sources of support
- A sense of hopelessness and negative view of the future means it is very difficult to find the motivation to try to make life better, especially in relation to their own wellbeing

It is very easy to get lost in thoughts about unhappy aspects of the past, especially during difficult times. As described earlier, in mindfulness when dealing with the effects of life's difficulties we often try to create a distance from our thoughts. Some people use images to help them do this, for example, thoughts and images falling like water in a waterfall; thoughts and images coming onto and leaving a stage; and thoughts and images floating down a stream on leaves or logs.

We can use our mindfulness skills when we experience ruminative-type thoughts:

1. Remind ourselves that thoughts are not fact and our thoughts aren't us
2. Notice the thoughts arising
3. Congratulate ourselves that we noticed our thoughts regardless of how long we got lost in them beforehand
4. If it helps then label them, for example, as judgements about ourselves
5. Try to let them go, but don't push them away
6. Start at number one again.....

### **Beautiful Boy**

*By John Lennon*

Life is what happens when you're busy making other plans

## **Breathing Space**

This is a short mindfulness practice to bring you out of automatic pilot and into the present moment. It is about three minutes long. There are three stages as described below.

### **1. Acknowledge**

Bring yourself into the present moment by asking "What is happening for me right now?" Check out any sensations in your body; any thoughts, or emotions regardless of whether they are positive, negative or neutral. Try not to want things to be different. Try to stay with your experiences and try not to flit too quickly from one aspect of your experience to another.

### **2. Gather**

Gently focus your attention on to your breathing. Notice the flow of air in and out of your body: the rise and fall of your belly, or any sensations in other areas of your body as you breathe in and out. The breath in this practice acts as an anchor, pulling you back to the present moment encouraging stillness and awareness of what is present.

### **3. Expand Awareness**

Expand your awareness around your breathing to include your whole body - torso; arms and hands; legs and feet, and head and face. You can expand your awareness of your whole body a bit at a time if that works for you. Then expand your awareness to the space around you. Hold your body and the space around you in awareness as best you can.

Some people like to ground themselves before and after this practice. To do this, notice an area of your body which is in contact with the earth directly or indirectly. So, if you are sitting you might focus your attention for a few seconds on the soles of your feet resting on the floor, or on your bottom resting on the chair.



## WEEK 5

### Home Practice

1. Do the mindfulness of body, thoughts and sounds practice 6 days out of the next 7.
2. Do the coping space practice at least once per day 6 days out of the next 7 - try to use it when you start feeling stressed / angry / frustrated etc.

### Values

Values are chosen life directions. So if you imagine that your life is a bus then your values would be the compass that keeps you going in the right direction. Because values are directions, your journey never ends. If you intended to dedicate your life to travelling east, you would never arrive anywhere called east rather you'd just keep going and going.

Sometimes it might be the case that your values cannot show themselves because of life circumstances. Travelling east you might come to a cliff face and have to change direction, or you might have to wait a while for a plane or boat to help you cross an ocean. Similarly, you might value being in an intimate relationship but be currently single.

Values aren't goals. However, you can make goals that reflect your chosen values. For example, if you value education and learning, then a goal might be getting a qualification but your journey can continue beyond this event because there are a million and one ways to continue to learn about our world. It's the same if you value being a loving parent, you don't just do it for one day and then move onto the next goal.

The values that you choose will to a large extent define your life, although no one can always live according to their values. The path isn't straight. Sometimes you will live by your values to a greater extent than at other times. That is just being human. Parenting is a great example - most of us are effective one day and less so

the next. It's important not to use values as another stick to beat yourself with. Remember one aspect of mindfulness is being kind to yourself.

One of the difficulties of trying to live a life in line with your values is that you become vulnerable. Unfortunately, values aren't always about feeling good. In fact people are generally distressed about aspects of their life which they value. So, most of us grieve when a loved-one dies, and we feel guilty if we judge negatively our efforts to parent. If we didn't care about close relationships or our children then we would not have these emotions.

Values give your life vitality and the great thing about them is that they do not require you to be free of emotional pain.

On the next page is a table listing 10 values that commonly people consider important to one extent or another. Think about each one and rate on a 10-point scale how important it is to you (0 = not at all important and 10 = extremely important) - place this figure in the column Importance. Then think about your current behaviour and rate how well you are actually living this value (0 = not at all showing in my behaviour and 10 = showing to a very large extent in my behaviour) - place this figure in the Current Behaviour column. Finally subtract the second figure from the first (Importance - Current Behaviour).

High numbers in the far right column often indicate sources of suffering. They reflect the fact that there is large difference between how important you think your values are and their actual presence in your life. It is in these areas that you might want to consider slowly reallocating your time and resources.

Domain	Importance	Current Behaviour	Score
Intimate relationship (marriage; partnership etc)			
Parenting			
Other Family Relations			
Friendship / Social Relationships			
Career / Employment			
Recreation / Leisure / Hobbies			
Spirituality			
Citizenship (involvement in community life)			
Education / Learning / Personal Growth			
Health / Physical Wellbeing			

### **Coping Space**

This is a short mindfulness practice to use when you feel troubled in some way as you go about your daily life. Try to remember the idea is to use this practice to relate differently to your experiences rather than to escape from them. Similar to the breathing space, it is about three minutes long and contains three stages.

#### **1. Acknowledge the Difficulty**

Bring yourself into the present moment by asking "What is happening for me right now?" Check out any sensations in your body; any thoughts, or emotions. Put your experiences into words, for example, "I can feel anger and frustration building up here" or perhaps "There's tension across my forehead" or even "I'm criticising myself a lot right now". Try not to want things to be different. So, you are observing and describing to yourself what is happening. Try to stay with your experiences and try not to flit too quickly from one aspect of your experience to another.

## **2. Redirect Attention**

Gently focus your full attention on to your breathing. Notice the flow of air in and out of your body: the rise and fall of your belly, or any sensations in other areas of your body as you breathe in and out. If you find it helpful, you can count as you breathe out. Go back to 1 if you lose count or reach 10.

## **3. Expand Awareness**

Expand your awareness around your breathing to include your whole body - torso; arms and hands; legs and feet, and head and face. You can expand your awareness of your whole body a bit at a time if that works for you. Then expand your awareness to the space around you. Hold your body and the space around you in awareness as best you can. Direct your breath to any negative sensations you are having in your body and allow a sense of softening. So, for example, if you are experiencing considerable negative sensations in your back then as you breath-in, direct the flow of air to this area. As you breathe-out, allow the muscles in this region to gently soften and open. Be kind to yourself at these times and try to directly face feeling uncomfortable (perhaps say to yourself "It's OK to feel this way").

You can ground yourself before and after this practice if you find it helpful.

## **Mindfulness of Body, Thoughts & Sounds**

This mindfulness practice has five parts. Initially, we centre ourselves by following our breath for a few minutes, before focusing attention on any body sensations that we become aware of. We then let go of our body sensations and as best we can focus awareness on our thoughts; followed by sounds, and then finally end with a period of following our breath again.

1. The first part of this practice is mindfulness of breathing. So, follow the instructions given earlier but only go as far as counting as you breathe out. Continue until you start to feel settled, say for a couple of minutes, or so.
2. On an out-breath, let go of following your breath and focus your attention on whatever bodily sensation come into the field of awareness. Try to notice them arise and notice any changes in the sensations from one moment to

another. Also, try to not want them to be different. Most people find that bodily sensations come and go and that new ones continually arise. If you can, try not flit too much from one sensation to another, rather try to stay with one specific sensation until it disappears.

3. After about seven minutes, on an out-breath let go of following your bodily sensations, and focus your attention on your thoughts. Notice when thoughts arise and watch them as they disappear. Try as best you can to see them as events continually coming and going. As usual, don't try to push thoughts away, or concern yourself if the same ones keep coming back. Also don't try to generate thoughts, they will arise naturally all by themselves.
4. Some people find it helpful to use imagery during this practice. For example, some people like to see this process in terms of thoughts arriving and leaving a stage or cinema screen. Other people imagine they are sitting on a riverbank and see this process as thoughts drifting along a river - coming into view and then fading into the distance. You might have your own ideas.....
5. After about seven minutes, as you breathe out, let go of watching your thoughts and re-focus your attention to sound. Notice sounds arising and fading; sounds that are close, and sounds that are further away. Try to pay attention to sounds that are loud and perhaps dominate space at times, but also to more subtle sounds too. Do this for about seven minutes.
6. As best you can, try to be aware of sounds as sensations. If you find yourself thinking about what they are (perhaps the image of the source of the sound; what the source of the sound is doing etc), try to reconnect with sensory qualities (pitch, loudness, duration and so on). Also try not to use your mind to search out sound (as you would use your eyes to locate objects), rather just sit and receive sounds.
7. You can also focus on the space around sound.
8. As usual, if you find that you are lost in your thoughts or bodily sensations, acknowledge whatever has distracted you and then return your attention to sound.



9. After about seven minutes, on an out-breath let go of attending to sound and just attend to whatever comes into your awareness, be it thoughts, body sensations or sounds. Again, try not to flit too much from one thing to another. Continue for about seven minutes.
10. On an out-breath, focus your attention on your breathing for a few minutes before opening your eyes.

### **Eternity**

*By William Blake*

He who binds himself a joy  
Does the winged life destroy.  
But he who kisses the joy as it flies  
Lives in eternity's sun rise



## WEEK 6

### The Future

During this course, you have been encouraged to develop your mindfulness skills. Often the more people practice and discuss this seemingly simple idea the more complicated it becomes. Hopefully you have a better idea now than when you started....

This course has emphasised awareness, attention and acceptance as routes to improved emotional wellbeing. Also, this course suggested that although your personal values are often the source of emotional pain, they give your life vitality and meaning. That's why avoiding sources of distress whether this be thoughts, feelings, events or people, almost always involves considerable personal costs. Avoiding and over-controlling usually mean not engaging with life to some extent or another, and creates extra layers of problems on top of the original ones.

Difficult times are inevitable for all of us, especially if we do our best to engage with life. At these times, we can easily revert to old habits that are often unhelpful. You might find it helpful to note down in the table overleaf the signs that your mood is dropping or stress levels are rising and what you could do to look after yourself at these times.

### References

If you would like to read more about mindfulness or mindfulness based approaches to life then below are a small number of books which we would recommend.

Kabat-Zinn, J. (1990). *Full Catastrophe Living: How to Cope with Stress, Pain and Living Using Mindfulness Meditation*. Piatkus Books Ltd: London.

Hayes, S. (2005). *Get Out of Your Mind and Into Your Life*. New Harbinger Publications: Oakland.

Williams, M., Teasdale, J., Segal, Z & Kabat-Zinn, J. (2007). *The Mindful Way Through Depression: Freeing Yourself from Chronic Unhappiness*. Guilford Publications: New York.

### **Warning Signs**

(For example, irritability, recurring negative thinking; disturbed sleep; endlessly rushing about; muscle tension; headaches; not wanting to see people etc)

### **Unhelpful Strategies**

(For example, overeating; avoiding; putting things off; working long hours; drinking too much; generally putting life on hold etc)

### **Helpful Strategies**

(For example, physical exercise; socialising; doing things you enjoy; doing activities which gives you a sense of mastery; generally making me-time; etc)

## **All Things Pass**

*by Lao-Tzu*

All things pass  
a sunrise does not last all morning  
all things pass  
a cloudburst does not last all day  
all things pass  
nor a sunset all night  
all things pass  
What always changes?  
Earth... sky.....thunder  
mountain....water..... wind  
fire.....lake  
  
These change  
and if these do not last  
  
Do man's vision  
Do man's illusions last?  
  
Take things as they come  
all things pass

***Congratulations on completing the course !***

## **APPENDIX 6**

Practice Diary

Mindfulness Based Stress Reduction: Practice Diary

Name \_\_\_\_\_

Please detail in the tables below the type of practice(s) you have undertaken each day and the duration. If you undertake more than one practice, please detail BOTH practices and the durations of each. If you are unable to complete a practice, please leave the corresponding box blank.

Also make a note of anything that comes up in the homework so that we can talk about it at the next meeting.

Week 1	Type of Practice(s)	Duration	Comments
Wednesday	1. 2.		
Thursday	1. 2.		
Friday	1. 2.		
Saturday	1. 2.		
Sunday	1. 2.		
Monday	1. 2.		



Week 2	Type of Practice(s)	Duration	Comments
Wednesday	1. 2.		
Thursday	1. 2.		
Friday	1. 2.		
Saturday	1. 2.		
Sunday	1. 2.		
Monday	1. 2.		

Week 3	Type of Practice(s)	Duration	Comments
Wednesday	1. 2.		
Thursday	1. 2.		
Friday	1. 2.		
Saturday	1. 2.		
Sunday	1. 2.		
Monday	1. 2.		

Week 4	Type of Practice(s)	Duration	Comments
Wednesday	1. 2.		
Thursday	1. 2.		
Friday	1. 2.		
Saturday	1. 2.		
Sunday	1. 2.		
Monday	1. 2.		

Week 5	Type of Practice(s)	Duration	Comments
Wednesday	1. 2.		
Thursday	1. 2.		
Friday	1. 2.		
Saturday	1. 2.		
Sunday	1. 2.		
Monday	1. 2.		

## **APPENDIX 7**

### **Demographic Questionnaire**

### **Background Information**

**Would you mind providing us with some information about yourself?**

**1. Name** \_\_\_\_\_

**2. Gender:** Male ☐ Female ☐

**3. Age :** \_\_\_\_\_

**4. What is your highest level of education?** School ☐ College ☐ University ☐

**6. Occupation:** *Please detail below*

Homemaker ☐ Full-time work (outside home) ☐ Part-time work (outside home) ☐

*Please specify current or most recent occupation (outside home) if relevant*

\_\_\_\_\_

**7. Which of the following best describes your current situation:**

Single parent ☐ Co-parent (living together) ☐ Co-Parent (living in different houses) ☐

**Would you mind providing us with some brief information about your child's condition?**

**8. What is the name of your child's condition?** \_\_\_\_\_

\_\_\_\_\_

**9. How old was your child when you were told that he or she had a medical condition?**

\_\_\_\_\_

## **APPENDIX 8**

The Hospital Anxiety and Depression Scale (HADS)

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help you more.

This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

*Tick only one box in each section*

**I feel tense or 'wound up':**

Most of the time .....  
A lot of the time .....  
Time to time, Occasionally .....  
Not at all .....


**I feel as if I am slowed down:**

Nearly all the time .....  
Very often .....  
Sometimes .....  
Not at all .....


**I still enjoy the things I used to enjoy:**

Definitely as much .....  
Not quite so much .....  
Only a little .....  
Hardly at all .....


**I get a sort of frightened feeling like 'butterflies' in the stomach:**

Not at all .....  
Occasionally .....  
Quite often .....  
Very often .....


**I get a sort of frightened feeling as if something awful is about to happen:**

Very definitely and quite badly .....  
Yes, but not too badly .....  
A little, but it doesn't worry me .....  
Not at all .....


**I have lost interest in my appearance:**

Definitely .....  
I don't take so much care as I should.....  
I may not take quite as much care .....  
I take just as much care as ever .....


**I can laugh and see the funny side of things:**

As much as I always could .....  
Not quite so much now .....  
Definitely not so much now .....  
Not at all .....


**I feel restless as if I have to be on the move:**

Very much indeed .....  
Quite a lot .....  
Not very much .....  
Not at all .....


**Worrying thoughts go through my mind:**

A great deal of the time .....  
A lot of the time .....  
From time to time but not too often ...  
Only occasionally .....


**I look forward with enjoyment to things:**

As much as ever I did .....  
Rather less than I used to .....  
Definitely less than I used to .....  
Hardly at all .....


**I feel cheerful:**

Not at all .....  
Not often .....  
Sometimes .....  
Most of the time .....


**I get sudden feelings of panic:**

Very often indeed .....  
Quite often .....  
Not very often .....  
Not at all .....


**I can sit at ease and feel relaxed:**

Definitely .....  
Usually .....  
Not often .....  
Not at all .....


**I can enjoy a good book or radio or TV programme:**

Often .....  
Sometimes .....  
Not often .....  
Very seldom .....


*Do not write below this line*



## **APPENDIX 9**

The Cognitive & Affective Mindfulness Scale-Revised (CAMS-R)

## CAMS-R

People have a variety of ways of relating to their thoughts and feelings. For each of the items below, rate how much each of these ways applies to *you* DURING THE PAST WEEK.

1	2	3	4
Rarely/Not at all	Sometimes	Often	Almost Always

- \_\_\_\_\_ 1. It is easy for me to concentrate on what I am doing.
- \_\_\_\_\_ 2. I am preoccupied by the future.
- \_\_\_\_\_ 3. I can tolerate emotional pain.
- \_\_\_\_\_ 4. I can accept things I cannot change.
- \_\_\_\_\_ 5. I can usually describe how I feel at the moment in considerable detail.
- \_\_\_\_\_ 6. I am easily distracted.
- \_\_\_\_\_ 7. I am preoccupied by the past.
- \_\_\_\_\_ 8. It's easy for me to keep track of my thoughts and feelings.
- \_\_\_\_\_ 9. I try to notice my thoughts without judging them.
- \_\_\_\_\_ 10. I am able to accept the thoughts and feelings I have.
- \_\_\_\_\_ 11. I am able to focus on the present moment.
- \_\_\_\_\_ 12. I am able to pay close attention to one thing for a long period of time.

## **APPENDIX 10**

The Acceptance and Action Questionnaire (AAQ)

## AAQ

Below you will find a list of statements. Please rate the truth of each statement as it applies to you. Use the following scale to make your choice.

1-----2-----3-----4-----5-----6-----7  
never very seldom seldom sometimes frequently almost always always  
true true true true true true true

- \_\_\_\_\_ 1. I am able to take action on a problem even if I am uncertain what is the right thing to do.
- \_\_\_\_\_ 2. A person who is really "together" should not struggle with things the way I do.
- \_\_\_\_\_ 3. When I feel depressed or anxious, I am unable to take care of my responsibilities.
- \_\_\_\_\_ 4. I try to suppress thoughts and feelings that I don't like by just not thinking about them.
- \_\_\_\_\_ 5. There are not many activities that I stop doing when I am feeling depressed or anxious.
- \_\_\_\_\_ 6. It's OK to feel depressed or anxious.
- \_\_\_\_\_ 7. It's unnecessary for me to learn to control my feelings in order to handle my life well.
- \_\_\_\_\_ 8. I rarely worry about getting my anxieties, worries, and feelings under control.
- \_\_\_\_\_ 9. In order for me to do something important, I have to have all my doubts worked out.
- \_\_\_\_\_ 10. I'm not afraid of my feelings.
- \_\_\_\_\_ 11. When I compare myself to other people, it seems that most of them are handling their lives better than I do.
- \_\_\_\_\_ 12. I try hard to avoid feeling depressed or anxious.
- \_\_\_\_\_ 13. Anxiety is bad.
- \_\_\_\_\_ 14. Despite doubts, I feel as though I can set a course in my life and then stick to it.
- \_\_\_\_\_ 15. If I could magically remove all the painful experiences I've had in my life. I would do so.
- \_\_\_\_\_ 16. I am in control of my life

## **APPENDIX 11**

Strengths and Difficulties Questionnaire: Classification System

**Classification System- SDQ Scales**

Scale	Normal	Borderline	Abnormal
Total Difficulties Score	0-13	14-16	17-40
Emotional Symptoms	0-3	4	5-10
Conduct Problems	0-2	3	4-10
Hyperactivity	0-5	6	7-10
Peer Problems	0-2	3	4-10
Prosocial Behaviour	6-10	5	0-4



## **APPENDIX 12**

The Strengths and Difficulties Questionnaire (SDQ)

## Strengths and Difficulties Questionnaire

P 4-16

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months.

Child's Name .....

Male/Female

Date of Birth.....

	Not True	Somewhat True	Certainly True
Considerate of other people's feelings	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Restless, overactive, cannot stay still for long	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often complains of headaches, stomach-aches or sickness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shares readily with other children (treats, toys, pencils etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often has temper tantrums or hot tempers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Rather solitary, tends to play alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally obedient, usually does what adults request	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many worries, often seems worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helpful if someone is hurt, upset or feeling ill	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Constantly fidgeting or squirming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has at least one good friend	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often fights with other children or bullies them	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often unhappy, down-hearted or tearful	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Generally liked by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Easily distracted, concentration wanders	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Nervous or clingy in new situations, easily loses confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kind to younger children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often lies or cheats	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Picked on or bullied by other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Often volunteers to help others (parents, teachers, other children)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thinks things out before acting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Steals from home, school or elsewhere	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gets on better with adults than with other children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Many fears, easily scared	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sees tasks through to the end, good attention span	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Do you have any other comments or concerns?

**Please turn over - there are a few more questions on the other side**

Overall, do you think that your child has difficulties in one or more of the following areas:  
emotions, concentration, behaviour or being able to get on with other people?

No	Yes- minor difficulties	Yes- definite difficulties	Yes- severe difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

If you have answered "Yes", please answer the following questions about these difficulties:

● How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

● Do the difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

● Do the difficulties interfere with your child's everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FRIENDSHIPS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CLASSROOM LEARNING	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LEISURE ACTIVITIES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

● Do the difficulties put a burden on you or the family as a whole?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Signature .....

Date .....

Mother/Father/Other (please specify:)

Thank you very much for your help

## **APPENDIX 13**

### **Course Evaluation Form**

## Course Evaluation Questionnaire

### **Research Study Investigating the Effectiveness of a Mindfulness Based Stress Reduction Course for Parents of Children with Medical Problems**

We would welcome your views on this mindfulness based stress reduction course to help us make sure we deliver a high quality course in future. We hope you will be constructive, open and frank in your comments.

#### Practical Aspects

**1. The course was held at a time that suited me:**

*Strongly agree*                      *Agree*                      *Disagree*                      *Strongly disagree*

**2. The location of the course was suitable to me:**

*Strongly agree*                      *Agree*                      *Disagree*                      *Strongly disagree*

#### Course Delivery/ Content

**3. The course facilitators were:**

**a) Warm and interested:**

*Strongly agree*                      *Agree*                      *Disagree*                      *Strongly disagree*

**b) Confident and knowledgeable:**

*Strongly agree*                      *Agree*                      *Disagree*                      *Strongly disagree*

**4. The content of the course was relevant to my situation:**

*Strongly agree*                      *Agree*                      *Disagree*                      *Strongly disagree*

**5. The material covered in the course was presented and discussed in a clear and coherent way:**

*Strongly agree*                      *Agree*                      *Disagree*                      *Strongly disagree*

**6. I had sufficient opportunity to participate in the group-based discussions:**

*Strongly agree*                      *Agree*                      *Disagree*                      *Strongly disagree*

**7. Looking back, the course was worth the time commitment:**

*Strongly agree                      Agree                      Disagree                      Strongly disagree*

**8. I have gained what I hoped to gain from the course:**

*Strongly agree                      Agree                      Disagree                      Strongly disagree*

***If you agree with the above statement, please detail what you feel you have gained from the course:***

**9. I have managed to incorporate mindfulness into my everyday life:**

*Strongly agree                      Agree                      Disagree                      Strongly disagree*

**10. Is there anything you would have liked to know about the course before agreeing to take part? Please detail below:**

**11. What did you like or find helpful about the course? Please detail below;**



**12. What aspects of the course did you find challenging? Please detail below;**

**13. I would recommend the course to someone in a similar situation as me?**

*Strongly agree*

*Agree*

*Disagree*

*Strongly disagree*

**14. What advice would you give to someone that was interested in our course?**

**14. Many mindfulness based stress reduction (MBSR) courses are 8-weeks long. Do you think you would have attended if you knew the course was 8-weeks long?**

Yes

No

Don't know

**15. Often in MBSR courses the home based practice lasts for 45 minutes each night. Would you be put off taking part in the course if the practices were 45 minutes per night (rather than 30 minutes)?**

Yes

No

Don't know

**16. Many mindfulness courses also include a mindful day, in which people take part in various mindfulness practices over the whole day.**

**a) Would you have liked to have attended a mindful day?**

Yes

No

Don't know

**b) Would you have been able to attend a mindful day?**

Yes

No

Don't know

**Any Other Comments on the Course Overall ?**

Thanks for your time!

Corrie Darbyshire

Andy Keen

## **APPENDIX 14**

Correspondence Granting Ethical Approval: Ethics Committee

## **North of Scotland Research Ethics Committee (1)**

Summerfield House  
2 Eday Road  
Aberdeen  
AB15 6RE

Telephone: 01224 558480  
Facsimile: 01224 558609

03 October 2007

Ms Corrie Darbyshire  
Trainee Clinical Psychologist  
NHS Grampian  
Child and Family Mental Health Service  
Royal Aberdeen Children's Hospital  
Aberdeen  
AB25 2ZD

Dear Ms Darbyshire

**Full title of study:** A mindfulness based treatment programme for parents of children with chronic illness: impact on parental wellbeing and perception of their child's behaviour.  
**REC reference number:** 07/S0801/105

The Research Ethics Committee reviewed the above application at the meeting held on 27 September 2007. Thank you for attending to discuss the study.

- You confirmed that it would be made very clear to the participants of the enormous time commitment involved with this study.
- You confirmed that if participants were very depressed then professional advice would be sought and offered.
- You confirmed that participants who wanted to take part but didn't meet the inclusion criteria would be looked at on a case by case basis.

### **Ethical opinion**

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

### **Conditions of approval**

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

The favourable opinion is given provided that you comply with the conditions set out. You are advised to study the conditions carefully, in particular:

## **APPENDIX 15**

Correspondence Granting Approval: R&D

## Research and Development

Foresterhill House Annexe  
Foresterhill  
Aberdeen  
AB25 2ZB



Date 11/10/07  
Ethics 07/S0801/105  
R&D Ref: 2007MH007

Ms Corrie Darbyshire  
Child & Family Mental Health Service  
Royal Aberdeen Children's Hospital  
Aberdeen  
AB25 2ZD

Enquiries to	Katy Booth
Extension	54656
Direct Line	01224 554656
Email	k.booth2@nhs.net

Dear Ms Darbyshire,

**Project title: A mindfulness based treatment programme for parents of children with chronic illness: impact on parental wellbeing and perception of their child's behaviour**

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS Grampian Research & Development Office. The project has R & D Management Approval to proceed locally.

Please note that if there are any other researchers taking part in the project that are not named on the original Ethics application, please advise the Ethics Committee in writing and copy the letter to us so that we may amend our records and assess any additional costs.

Wishing you every success with your research

Yours sincerely

A handwritten signature in black ink, appearing to read 'K. Booth' with a stylized flourish at the end.

**Katy Booth**  
**Data Co-ordinator**